

TINY BABIES: THE IMMENSE COSTS AND QUANDARIES OF PRETERM BIRTH AND LOW BIRTH WEIGHT

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A thesis submitted to the faculty of the University of North Carolina at Chapel Hill in
partial fulfillment of the requirements for the degree of Master of Arts in the School of
Journalism and Mass Communication

Chapel Hill
2008

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ABSTRACT

JULIA CONNORS: Tiny Babies:

The Immense Costs and Quandaries of Preterm Birth and Low Birth Weight

(Under the direction of Jan Yopp, Andy Bechtel and Dr. Matt Laughon)

Preterm birth and low birth weight are growing problems in the U.S. Popular media representations of issues surrounding these conditions have typically been limited to reporting the release of statistics and the results of individual studies. However, the media have not successfully conveyed the complexity, severity or personal nature of these problems. This thesis, which is comprised of four print articles, explores three aspects of preterm birth and low birth weight that media have largely underreported. First, the thesis examines the personal experience of having a preterm, low birth weight baby, including the emotional, physical and financial costs. Second, it contextualizes the complexity of this phenomenon by examining risk factors, lack of prevention, and short- and long-term health problems associated with preterm birth and low birth weight. Lastly, this thesis investigates the role of ethics, decision-making regarding care and quality of life related to these conditions.

With love for Jeff Soplop, my very-soon-to-be-husband.

ACKNOWLEDGEMENTS

I would like to extend my gratitude to several people without whom this project would not have been possible. First, thank you to my thesis chair, Jan Yopp, for her undying encouragement, enthusiasm and copy editing. I would also like to thank my thesis committee, Andy Bechtel and Dr. Matt Laughon, for their invaluable input and support. I could not have completed this project, let alone this master's program, without the companionship of my journalism school colleagues. I owe endless thanks—and probably endless money for lengthy phone bills—to my parents, Connie and Tim, and my sisters, Erin, Megan and Mari, for being my foundation. My fiancé, Jeff Soplop, deserves heaps of praise for reading drafts and constantly calming my nerves. My memories of a little girl named Caroline Carisch keep me doing what I'm doing. I am also grateful to Angela Williams and Melanie Purvis for allowing me a glimpse into their lives as parents of preemies. And above all, thank you to two beautiful reasons that this project matters: Halle Purvis and Jada Williams.

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INTRODUCTION

The U.S. is considered the place to come for health care requiring advanced technology. But many indicators reveal that the U.S. has a generally less-than-adequate health care system combined with a relatively unhealthy population, and our youngest residents may be among some of the most vulnerable to these deficits. Despite advances in medical care, too many babies are born well before the gestational age considered adequate for proper fetal development. A normal pregnancy lasts 38 to 42 weeks, and babies born before 37 weeks are considered premature or preterm. Those born before 23 weeks almost never survive.

A decade ago, Dr. Jay Iams wrote an editorial in *The New England Journal of Medicine*, which began: “Advances in care of preterm infants have blunted what otherwise should have been a constant public outcry about the static rate of preterm birth, the leading cause of perinatal and infant morbidity and mortality in the United States. Why has the problem of prematurity not been solved?” He hit on a topic that should be of growing concern in this country, especially since the rate of preterm birth is actually far from leveling off. In fact, the rate has increased by one-third since 1981, according to Centers for Disease Control and Prevention data. Today, nearly one out of eight babies born in the U.S. arrives preterm.

Preterm birth accounts for one-third to two-thirds of infant deaths in this country—a serious problem since the U.S. has the second-highest infant mortality rate in the developed world (Callaghan et al., 2006; Save the Children, 2007). Preterm birth also

causes around half of all congenital neurological disabilities (Goldenberg & Rouse, 1998). The health bill for preterm infants and their resulting medical conditions costs the U.S. an estimated \$26 billion a year—a figure that doesn't include the subsequent lifelong costs of medical therapies or other needs (Institute of Medicine, 2006).

Most preterm babies are also low birth weight, a condition that itself can be dangerous. Low birth weight babies, who comprise one out of 13 births in this country, arrive weighing fewer than 5 pounds 8 ounces, or 2,500 grams. Around two-thirds of low birth weight babies are preterm, while the other third are small-for-gestation, that is, they are born full-term. Very low birth weight infants arrive weighing fewer than 3 pounds 5 ounces, or 1,500 grams. The risk of a very low birth weight infant dying during the first year of life is nearly 100 times as great as it is for a normal weight infant (Martin et. al, 2006).

While women of any age, race or socioeconomic status can have a preterm or low birth weight baby, traditionally, preterm birth has often been viewed as a problem of teenage minorities. Black women are more likely than white women to deliver preterm and are twice as likely as white women to deliver a low birth weight infant, according to the CDC. But in recent years, fewer black teenagers are delivering babies, and the incidence of teenagers, both black and white, having preterm and low birth weight babies has not grown as fast as the rates for older women. The increase in preterm birth and low birth weight rates has been largely attributed to delayed childbearing because black and white women are having babies at more advanced ages and to the increased use of assisted reproductive technology. Both trends have raised the incidence of multiple births, another major risk factor for preterm birth and low birth weight. While the spike in

multiple births has contributed to these increasing rates, more singletons, or single baby births, are also delivering too early and too small (Hamilton et al., 2006).

One of the greatest risk factors for preterm birth is a previous preterm birth (Adams et al., 2000). The CDC's Healthy People 2010 calls for a reduction in the preterm birth rate to no more than 7.6 percent of live births, compared to today's rate of nearly 13 percent of live births, as well as a reduction of the low birth weight rate to no more than 5 percent of live births, as compared to today's rate of 8 percent of live births. The risk factors for these conditions are complex and interrelated, and the processes not well understood, so little progress has been made in preventing or reducing them.

The urgency to reduce the incidence of preterm birth and low birth weight should be considerable because the associated health consequences can lead to a dramatically reduced quality of life for these infants and their families. Preterm and low birth weight infants face myriad challenges as they enter a world their bodies are unprepared to handle. They struggle to survive outside the womb. Many of their organs have not fully formed, they can't maintain body temperature, and their swallow reflexes have not yet developed. They are fed by tube. Often times, even breathing is a task they can't accomplish without mechanical assistance. During the first few weeks of life, they are at risk for improper lung function, brain bleeds and dangerous intestinal problems, among other issues.

Underdeveloped lungs are one of the greatest dangers of preterm birth. But several significant medical advances over the last decade or two have allowed physicians to save babies at younger gestations and lower birth weights. For example, the use of prenatal corticosteroids—that is, the administration of steroids to pregnant woman at-risk

for preterm labor—have been shown to accelerate fetal lung maturation. The steroids also decrease the incidence of respiratory distress syndrome and the need for mechanical ventilation in preterm infants (Stiles, 2007). One of the most noteworthy developments, surfactant therapy, was approved by the Food and Drug Administration in 1990 and has since become a part of routine neonatal care. The substance surfactant naturally occurs in the lungs and helps ensure proper function, but preterm infants often have inadequate levels of it to breathe sufficiently. Surfactant therapy, which helps provide adequate levels of the substance to improve lung function, has been shown to reduce significantly morbidity and mortality from respiratory distress syndrome (Jobe, 1993).

These interventions, among others, produced such positive survival outcomes in preterm infants that they quickly became the norm. Babies are now surviving as young as about 23 weeks gestation and as small as around 400 to 500 grams, or 14 to 18 ounces (ACOG, 2002). But survival does not necessarily equate to a normal, healthy future. Many infants live with severe lifelong morbidities often associated with preterm birth and low birth weight, such as mental retardation, cerebral palsy, attention deficit hyperactivity disorder, blindness and deafness. Little progress has been made in treatments to decrease these lifelong health risks. In fact, besides the use of vitamin A supplements to reduce the risk of chronic lung disease in low birth weight infants, many interventions performed in the neonatal intensive care unit, or NICU, have not been demonstrated to improve lifelong outcomes. Typical interventions range from mechanical ventilation, to heart surgery, to drug therapy, to long-term medical and behavioral therapy. Given the state of the U.S. health care system, the immense costs associated with treating these conditions, often covered by Medicaid, may be unsustainable in the long-run.

In her 2003 book, *Saving Very Premature Babies: Key Ethical Issues*, Pauline Mifflin asks some hard questions: “Do rapid advances in both antenatal and neonatal technology mean that we have the means to phase out one set of abnormalities, only to be faced with another, potentially more serious set? What, if any, are the long-term implications of these breakthroughs for the child, the family and society in general?”

As growing numbers of preterm and low birth weight infants survive and are left with severe disabilities, the reality brings up ethical issues relating to quality of life. Should all babies at the threshold of viability be saved because it is technically possible? Should more discretion be used in determining when to resuscitate an infant who may experience a poor quality of life? Who should be making such decisions? And who should be financially responsible for them?

Popular media have reported the release of statistics, the latest medical developments and individual studies related to preterm birth and low birth weight, but they have not reported sufficiently on certain risk factors that can increase the chances that a baby will be born preterm. They have largely failed to cover the emotional, physical and financial costs associated with these tiny babies and their growth—factors that could influence women and their prenatal health care. They have also neglected the ethical questions regarding quality of life that are becoming increasingly important in the field of neonatology. This thesis intends to help fill that gap.

Literature Review

This review will explore scientific literature on four core issues as they pertain to preterm birth and low birth weight. First, it will address risk factors that have been associated with these conditions. Second, it will examine associated morbidity and

mortality. Next, it will address cost and ethics. Finally, it will investigate popular media coverage of preterm birth and low birth weight.

Contributing factors

Many factors, which span biological, behavioral and socioeconomic conditions, have been associated with preterm birth and low birth weight. Some of these factors can be managed, such as pre-pregnancy weight and smoking during pregnancy. Others can be interrelated and difficult or impossible to minimize, such as socioeconomic status and a prior preterm birth. In addition, some of these demographics and characteristics have become more or less significant over the last few decades. Although population-level statistics indicate higher risk associated with certain factors, no prediction methods have been developed to assess whether an individual woman will deliver early (Institute of Medicine, 2006). But women can be made aware of their risk factors.

Previous preterm birth

A previous preterm delivery increases a woman's risk of having a subsequent preterm baby (Adams et. al, 2000; Goldenberg et al., 1998). In fact, some authors have suggested that previous preterm birth carries the highest population attributable risk for another preterm birth (Facco et al., 2007). In a study by Adams et al. (2000), 20 percent of white women and 26 percent of black women whose first pregnancies ended in preterm delivery also delivered their second baby preterm. A woman's risk of preterm delivery of a subsequent baby, and how severely preterm that baby is, may depend on how early the previous baby arrived. Similarly, Facco et al. (2007) suggest that preterm twins are associated with an elevated risk of a subsequent preterm singleton delivery. McManemy et al. (2007) showed that two previous preterm singleton deliveries were

associated with up to a 42 percent chance of recurrence with a third singleton pregnancy. Another study demonstrated that the risk of preterm birth increases with an inadequate interpregnancy interval (DeFranco et al., 2007). The authors suggest women should wait at least 12 months between a term or preterm delivery and subsequent conception to reduce this risk.

Race

Research has demonstrated that women of different races have varying likelihoods of delivering preterm and low birth weight babies. Black women are more likely than white or Hispanic women to have either. Preliminary 2005 data from the CDC indicate that 18.4 percent of babies born to black women that year were preterm, compared to 11.7 percent of white babies and 12.1 percent of Hispanic babies. Black women were twice as likely to deliver low birth weight babies (14 percent) as white women (7.3 percent) or Hispanic women (6.9). According to a study by Schempf et al. (2007), the rate of extremely preterm births (fewer than 28 weeks gestation) was four times higher in blacks than in whites. Kistka et al. (2007) showed that even when controlled for maternal medical problems and socioeconomic status, black women were still more likely than white women to deliver preterm infants. In short, they suggest that race is an independent risk factor for preterm birth. They also found that black women were more likely to deliver at earlier gestations than white women, and it was more likely that their subsequent pregnancies would result in preterm birth. Similarly, Colen et al. (2006) found that upward socioeconomic mobility in white women resulted in a 50 percent decrease in the probability of having a low birth weight baby. In blacks, the same upward socioeconomic movement did not result in a statistically significant risk

reduction. Branum and Schoendorf (2002) demonstrated that the gap between preterm birth and low birth weight in blacks and whites decreased slightly from 1981 to 1998. During that time, the low birth rate in white singleton infants increased by 12 percent but remained fairly constant among black infants. The rate of preterm births for white singleton infants also increased by nearly 25 percent, but the rate for black infants only increased by 3 percent. These rates increased more for multiple births, regardless of race. The overall rates for black infants remained higher than those for white infants.

Age

Research has shown that teenagers and women 35 years and older are at an increased risk for adverse birth outcomes, including delivering preterm and low birth weight infants. According to the National Center for Health Statistics, from 2002 to 2004 the percentage of all babies born preterm was 12.3 percent (March of Dimes, 2007). However, the rate of preterm births to mothers over 40 years was 16.3 percent, and the rate for women under 20 years was 14.3. The trend was similar for low birth weight. During those years, 7.9 percent of all infants born were low birth weight. But 11.2 percent of infants born to mothers over 40 years were low birth weight, as were 9.8 percent of those born to mothers younger than 20 years (March of Dimes, 2007).

National Vital Statistics data (2002) show that in recent decades, more and more women are delaying childbearing. From 1980-2000, the percentage of births to teenagers decreased, especially among blacks (Hamilton et al., 2006). But during that same period, the percentage of births to women 35 years and older more than doubled among black women and tripled among white women (Martin et al., 2002). Yang et al. (2006) suggest

that as more women delay childbearing, the factor will play an even more substantial role in higher low birth weight rates.

Multiple births and assisted reproductive technology

Research indicates that multiple births are associated with a greater risk of preterm birth and low birth weight. Multiple births are six times as likely as singletons to be preterm and nine times as likely to be low birth weight (March of Dimes, 2007). From 1994 to 2004, the ratio of multiple births to singleton births increased by one-third. Almost 62 percent of multiple births are preterm, and 59 percent are low birth weight. Two major factors have contributed to the increase. First, women who become pregnant in their late 30s and 40s are more likely than younger women to conceive spontaneous multiples (Blondel et al., 2002). An estimated one-quarter to one-third of the increase in multiple deliveries in recent years has been attributed to advanced maternal age.

In addition, the use of assisted reproductive technology (ART) has boomed, and an estimated one in 80 to 100 births in the U.S. now results from it (Van Voorhis, 2007). ART is associated with higher rates of multiple births. Although the number of babies conceived through ART (resulting in about 48,000 births per year) in the U.S. is small compared to the number of total babies born each year (around 4 million births), the technology has had a large effect on the proportion of multiples born (Van Voorhis, 2007; Hamilton et al., 2006; Rebar & DeCherney, 2004). By 1997, more than 40 percent of triplets born in the U.S. were conceived using ART (CDC, 2000a). In 2003, nearly a third of pregnancies conceived by in vitro fertilization resulted in twin gestations and 3 percent resulted in triplet or higher order births, as compared to around 1 to 3 percent of spontaneous pregnancies resulting in multiple births (Van Voorhis, 2007). Scheive et al.

(2002) suggest that ART contributes to increases in low birth weight and very low birth weight rates for two reasons. First, ART increases the number of multiple gestations, primarily because multiple embryos per cycle are often implanted. Second, even singleton babies conceived using ART were more than twice as likely to be low birth weight than the general population of singletons born in the U.S. Singletons conceived through ART are also about twice as likely to be born preterm as those conceived spontaneously (Jackson et al., 2004).

Maternal medical characteristics

A host of additional maternal conditions—many of which are also indicators of an unhealthy population—have been associated with preterm birth and low birth weight. For example, preeclampsia, diabetes, infections, obesity, inadequate weight gain and stress can contribute to preterm birth and low birth weight (Institute of Medicine, 2006; ACOG, 2000). Behavioral factors, such as the use of alcohol, cigarettes and illicit drugs, can also contribute to the problem (ACOG, 2000; March of Dimes, 2007). Socioeconomic factors, such as low income and lack of education, have also been linked. In addition, fetal conditions, such as birth defects, placental problem and infections, such as rubella and chickenpox, have been associated with preterm birth and low birth weight.

The degree to which these risk factors are present in a certain population may depend on demographics and even geographical conditions. For example, Colorado has one of the highest low birth weight rates in the nation, according to the Colorado Department of Public Health and Environment. A report released by the department in 2000 found that inadequate weight gain and smoking represented the greatest attributable risk to low birth weight within the state's population. The department also identified

several other factors that affect birth weight in the state, such as living at high altitude, which can slow intrauterine growth.

Morbidity and mortality

Preterm birth and low birth weight can result in disastrous short- and long-term consequences. Both conditions increase the risk of morbidity and mortality. In fact, Callaghan et al. (2006) concluded that preterm birth accounted for more than one-third of infant deaths in 2002, making it the most frequent cause of infant death. Other estimates put the contribution of preterm birth to infant death closer to two-thirds (Goldenberg & Rouse, 1998). The U.S. has the second-highest infant mortality rate in the developed world, and the death rate for black infants is twice that of the general U.S. infant mortality rate (Save the Children, 2007). In 2002, the infant mortality rate rose to 7 per 1,000 live births, up from 6.8 per 1,000 live births in 2001. Martin et al. (2005) attributed this increase, the first in four decades, to growing numbers of singleton and multiple low birth weight deliveries under 750 grams. Very low birth weight infants are 100 times as likely as normal weight babies to die during their first year of life (Martin et al., 2006).

Since the development of certain lifesaving technologies, such as surfactant and prenatal steroids, infants are considered viable around 23 weeks gestation. Fanaroff et al. (2007) examined morbidity and mortality in relation to birth weight and gestational age. The authors found that risk of morbidity and mortality for study infants born between 1997 and 2002 decreased with each additional week of gestation and 100-gram increase in birth weight, and that males had a higher risk of mortality than females. Of the very low birth weight infants, 85 percent survived to discharge from the hospital, though the rates ranged from 55 percent of infants born at 501-750 grams to 96 percent for infants

born at 1,250-1,500 grams. Approximately 30 percent of the infants developed significant neonatal morbidities.

The risk of several major neonatal morbidities increases with the severity of preterm birth and low birth weight. The most common, bronchopulmonary dysplasia, known as chronic lung disease, is defined by a baby's continued need for supplemental oxygen at 36 weeks post-conception (Fanaroff et al., 2007). Interventions can include the use of surfactant and mechanical ventilation because preterm infants' lungs can be dangerously underdeveloped. Babies with chronic lung disease are more likely than babies without chronic lung disease who were delivered at the same gestational age to be hospitalized within the first year after discharge, have ongoing lung problems, such as asthma, and also suffer from neurological impairment. Intraventricular hemorrhage, IVH, or bleeding in the brain, can occur during the first few days after birth. IVH can resolve itself, but severe bleeds can lead to brain damage and may require medication or surgical intervention. Necrotizing enterocolitis, NEC, is another serious complication of preterm birth and low birth weight. An intestinal problem that typically develops within two to three weeks after birth, NEC can lead to feeding difficulties. It may require antibiotics or, in extreme situations, surgery to remove pieces of the intestine.

Other in-hospital morbidities also occur that are less serious but still common. All babies are born with a large artery in the heart that is not completely sealed, but it typically closes within a few days after birth. However, in preterm babies, the artery does not always close immediately. This condition is known as patent ductus arteriosis, or PDA. PDA is often treated with drugs or surgery. Another common problem is

retinopathy of prematurity, or abnormal blood vessel growth, that can lead to vision loss, though this condition often heals itself.

Infants with some of the most serious in-hospital conditions, such as chronic lung disease, IVH and NEC, are at an increased risk for developing serious long-term neurodevelopmental and behavioral problems, such as mental retardation, attention deficit hyperactivity disorder, blindness and deafness (Fanaroff et al., 2007). Several authors have explored the frequency and severity of these morbidities. Approximately half of all congenital neurological disabilities have been attributed to preterm birth (Goldenberg & Rouse, 1998). In a review article, Marlow (2003) states that the most common disability two years after very preterm birth is developmental or cognitive impairment, which can lead to poor school performance. In a meta-analysis, Bhutta et al. (2007) demonstrated that children who were born preterm and low birth weight performed significantly worse on cognitive tests than did children born at term. Their mean cognitive scores were directly proportional to their birth weights and gestational ages. In addition, children born preterm exhibited increased incidence of attention deficit hyperactivity disorder and other behavioral problems. Similarly, Hack et al. (2002) found that young adults born at very low birth weight did not outgrow their mental or physical disabilities. They were also less likely than normal birth weight peers to graduate from high school (74 percent versus 83 percent), and they exhibited higher incidence of neurosensory impairment (10 percent versus less than 1 percent).

Long-term physical impairments of preterm and low birth weight babies have also been cited in the literature. Cerebral palsy, which can cause loss of movement and other nerve function, occurs in about 8 to 10 percent of very low birth weight infants (Marlow,

2003). In a Dutch study, Rijken et al. (2006) found that the growth of preterm babies at 2 years of age was impaired: Length, weight and weight-for-length were significantly impaired compared to average Dutch children's growth charts. Catch-up growth occurred mostly during the first year; after that point, little catch-up growth occurred. The authors also found an association between growth retardation in length and weight and abnormal neurological examination. Smaller head circumference was associated with mental and psychomotor delay. Cardiovascular problems throughout the lifespan, such as high blood pressure, impaired cardiac function, differences in cardiac anatomy and a heightened risk of coronary events, have also been documented in people born preterm or low birth weight (Johansson et al., 2005; Mikkola et al., 2007; Barker et al., 2005).

Kaaresen et al. (in press, 2007) conducted a trial of an early intervention program for low birth weight children designed to improve cognitive, motor and behavioral outcomes. Outcomes at 2 years of age showed no significant improvement on any of those measures.

Although research has identified long-term neurodevelopmental, behavioral and physical morbidities in children and young adults born preterm or low birth weight, specific techniques for determining which individual babies will develop long-term morbidities have not yet been developed. For this reason, parents are often left unaware of the potential complications their infant may experience—and the cost of necessary interventions—when they bring their baby home from the hospital. The lifelong physical, psychological and financial impacts on these children and their families can be immense. Long-term morbidities associated with preterm birth and low birth weight may also have financial implications for U.S. educational systems and social services.

Cost and ethics

Preterm birth is expensive for families and society. An Institute of Medicine (2006) study showed that in 2005, preterm birth cost the United States more than \$26 billion, or \$51,600 per infant. Those costs were distributed among the following categories: medical care, maternal delivery, early intervention services, special education services, and lost household and labor market productivity (March of Dimes, 2007). The two highest expenses were attributed to medical care, which accounted for 65 percent of the total cost, or nearly \$17 billion, and lost household and labor market productivity, which accounted for 22 percent of the cost, or \$5.7 billion. The average length of stay in-hospital for a preterm infant is nine times that of a term infant: 13 days compared to 1.5 days. During the first year of life, in-patient and out-patient medical care for a preterm baby costs around 10 times as much as that for a term baby: \$32,325 versus \$3,325.

The burden of paying these costs is spread across individuals, employers, health plans, and federal and state Medicaid programs. Medicaid covered around 42 percent of preterm births in 2001 (Russel et al., 2007). The costs from the other half of preterm births are billed to employers and other private insurers. Another study showed that during the first year of life, preterm babies see physicians 50 percent more than term babies do (March of Dimes, 2005). The study also showed that on average, mothers of preterm babies spent 29.1 days out of the office during the six months following the birth, as compared to 18.9 days that mothers spent out with a term baby. That loss of time at work translated to a wage loss of \$1,513 per preterm infant. These numbers represent care for one year of life, but many preterm and low birth weight infants require extreme amounts of lifelong medical care.

The extremely high costs—financial, physical and emotional—of preterm birth and low birth weight beg the question of where limited resources should be devoted. Should they be put toward trying to save babies earlier and earlier? Toward minimizing long-term morbidities? Toward preventing preterm birth and low birth weight all together? Author upon author have suggested that resources should be allocated toward prevention (Institute of Medicine, 2006; Iams, 1998). After all, prevention is far less expensive than the lifetime costs of preterm birth and low birth weight. However, efforts to prevent preterm birth have largely failed (Institute of Medicine, 2006). Even regular prenatal care has not been demonstrated to improve long-term outcomes for these children (Goldenberg & Rouse, 1998; McCormick & Richardson, 2002).

The Institute of Medicine (2006) suggested that understanding and preventing preterm birth will require a multidisciplinary approach involving research into biological, psychological, social and environmental factors. In addition, it will require an improved understanding of the causes, biological pathways, diagnosis and treatment. There is one exception to this general failure of reducing preterm birth and low birth weight, but only in women who have previously delivered preterm. A weekly injection of 17 alpha-hydroxyprogesterone caproate, a hormone therapy known as 17P, to pregnant women who have had a previous preterm delivery has been shown to significantly reduce subsequent preterm birth (Meis et al., 2003). The drug has also been shown to significantly decrease severe morbidities in preterm infants, such as IVH, NEC and the need for supplemental oxygen.

Since no further successful prevention techniques have been developed, attention must be turned to the situation at hand: More preterm and low birth weight babies are

surviving than at any other time, but many of them live with long-term disabilities. Since the mid-1990s when new technologies allowed greater numbers of very preterm and very low birth weight babies to be saved, little progress has been made in reducing long-term morbidities (Fanaroff et al., 2007). As a result, some researchers are wondering if technology has gone too far. Are we saving babies whose quality of life will be so low that that they should never have been resuscitated? Some suggest that evidence-based research can help physicians and parents make difficult decisions about whether to resuscitate an extremely preterm infant. According to the American College of Obstetricians and Gynecologists' guidelines, *Perinatal Care at the Threshold of Viability* (2002), the following information should be considered when making these decisions. Infants born at 21 weeks gestation have a 0 percent chance of survival, and infants born at 25 weeks have a 75 percent chance of survival. Those born weighing 401-500 grams have an 11 percent chance of survival, while those born weighing 701-800 grams have a 75 percent chance of survival. Females generally do better than males. Infants delivered before 24 weeks are less likely to survive, and if they do, they are more likely to develop long-term morbidities. Half of extremely preterm infants develop neurodevelopmental and motor impairment.

However, these guidelines are limited to facts, to probability, to numbers. They do not speak of the ethical questions that surface when determining whether saving a life because technology allows it is more ethical than considering the possibility of dramatically reduced quality of life before making a decision. In her book, *Saving Very Premature Babies: Key Ethical Questions*, Mifflin (2003) discusses the four guiding principles of medical ethics: beneficence, non-maleficence, respect for autonomy and

justice. Beneficence means doing good for others, while non-maleficence means not harming them. Some authors have argued that in neonatal care, technology that saves a life may actually cause harm when long-term outcomes are considered (Miller, 1996; Mitchell, 1986). Respecting autonomy is allowing people to make decisions for themselves about whether they want to be helped. Because premature babies are unable to make decisions for themselves, the question becomes who should make decisions for them. Some authors have stated that parents should make these decisions for an infant, while others have argued that health professionals are in a better position to do so (Mifflin, 2003). Tyson (1995) stated that parents and health professionals should make the decision together. Unlike the other three principles, which focus on individual rights, justice expands those rights to society (Mifflin, 2003). It demands how resources should be distributed throughout society. Should hospitals spend their resources on a few very ill preterm babies who are more likely to develop expensive long-term disabilities? Or should they allocate more money to saving healthier babies who will be less costly in the future? For parents of preterm babies, the question becomes whether they can handle the emotional and financial costs of a baby with severe long-term disabilities because they will shoulder much of the cost.

But the four principles of medical ethics often contradict each other when making decisions about preterm infants at the edge of viability. Tyson and Stoll (2003) suggest that rather than relying on conflicting ethical principles, intuition and expert opinion when making real-life decisions about preterm babies born on the edge of viability, evidence-based ethics may be a better approach. Evidence-based ethics describes the concept of using the best evidence available on the effects of intensive care on these

infants and their expected outcomes to make ethical decisions. Applying this technique would mean considering factors such as gestational age, sex, birth weight, birth weight by gestational age, whether and when the baby received steroids before birth to quicken lung maturity, and whether the baby is a singleton versus a multiple. Depending on these factors and combinations of factors, a baby has a better or worse chance of benefiting from intensive care. Using this approach, intensive care is provided only when credible evidence indicates the “benefits outweigh the burdens” (Tyson & Stoll, 2003).

This approach comes with its own limitations. First, babies born at hospitals that offer higher levels of care have a better chance of survival (Phibbs et al., 1996). Also, different hospitals have different definitions of and policies toward viability, which may influence decisions made by parents and health professionals. In addition, gestational age is one of the more important factors used to determine viability, but estimated gestational age is not always accurate. Lastly, babies born younger and smaller than other babies are statistically more likely to develop long-term disabilities. However, physicians are not yet able to determine which individual babies will have the poorest outcomes.

Saroj Saigal et al. (1994, 1996, 2006) produced a series of follow-up studies of extremely low birth weight infants aimed at examining quality of life. They followed a cohort of around 160 Canadian infants born between 501 grams and 1000 grams. Looking at both functional and health-related quality of life outcomes, the researchers followed these infants through school-age, adolescence and early adulthood, comparing their outcomes to a control group of normal birth weight peers.

When the children were around 8 years old, the researchers developed objective methods to assess how health care providers perceived the health status and health-related

quality of life of these children. Of the extremely low birth weight group, 27 percent of the children had neurodevelopmental disabilities, compared to just 2 percent of children in the control group. The health care professionals perceived that children born extremely low birth weight experienced a significantly lower health-related quality life than did the control group of normal birth weight children. When the children became adolescents, Saigal et al. followed up with them again (1996). This time, they developed the first study to assess objectively health status and health-related quality of life from the perspectives of the children and parents themselves. They found that overall, the extremely low birth weight cohort rated themselves as having a significantly lower health-related quality of life than their control group peers. However, the majority of the individuals in the extremely low birth weight group actually rated themselves as having a quite satisfactory quality of life—one that was indistinguishable from the control group ratings. When Saigal et al. (2006) studied the cohort in early adulthood, they found the adults born extremely low birth weight, despite their disabilities, had only minor differences in educational attainment, employment and behavioral issues compared to normal birth weight controls, but those differences were not statistically significant. The majority of them were even living independently. Their quality of life ratings were indistinguishable from the ratings of the control group.

These findings, coupled with the vast world of unknowns when it comes to the outcomes of preterm and low birth weight infants, present great ethical challenges for parents and health professionals and have become a focus of increased discussion regarding quality of life.

Popular media representation

Popular media representations of issues surrounding preterm birth and low birth weight have typically been limited to reporting the release of statistics about infant mortality and preterm birth and the results of individual studies. For example, in a CNN.com article, “U.S. has second worst newborn death rate in modern world, report says,” Green (2006) wrote up the study and compared the U.S. rates to those of other developed nations. Also in 2007, BBC News reported a study that made a possible association between low birth weight and stress induced by the Sept. 11 terrorist attacks. The article did not mention the dangers of low birth weight. Writing for *The New York Times*, Bakalar (2007) produced a story on a specific study about black women having higher rates of preterm birth than white women. The story discussed the possibility of underlying genetic factors contributing to the differing rates between blacks and whites but again did not mention the dangers of preterm birth. The year before, Brody (2006) wrote about a March of Dimes program designed to ease the emotional burden of parents with babies in the NICU. The article discussed the rising rates of preterm birth, some risk factors contributing to the increasing rates, the preterm birth contribution to infant mortality rates and the emotional toll preterm birth can take on parents. The article failed to discuss the possibilities of long-term disability for those infants who survive. Maugh (2006) reported the release of an Institute of Medicine report for the *Los Angeles Times*, touching on preterm birth definitions rates, causes, racial differences, costs, potential morbidities and the U.S. mortality rates. Although the statistical reporting was strong, the author failed to use any personal anecdotes that could draw in readers and allow them to understand the true impact preterm birth can have on a family. Overall, media coverage

of preterm birth and low birth weight has been insufficient. It has concentrated on the release of individual studies and statistics but has failed to touch on other compelling issues, such as the fact that prevention has been unsuccessful and many preterm infants live with disabilities that are costly, both financially and emotionally. Popular media have also avoided the tough but crucial topics of ethics relating to quality of life.

Summary

This literature review has revealed several issues surrounding preterm birth and low birth weight. First, although multiple risk factors have been associated with preterm birth and low birth weight, and researchers and physicians agree that prevention is the best approach for solving problems related to these conditions, effective methods of prevention have not been developed. In fact, societal factors such as delayed childbearing and the use of assisted reproductive technology have actually led to significant increases in preterm birth and low birth weight over the last three decades. The costs of these conditions are enormous. Advances in technology have saved babies down to 23 weeks of gestation, so growing numbers of preterm babies are surviving each year. However, advances in lifesaving technology have not been followed by reductions in severe long-term morbidities, such as neurodevelopmental, physical and behavioral disabilities. Therefore, more preterm and low birth weight infants are surviving with disabilities. This fact begs the question of whether all infants who can technically be saved should be—the question of whether more selectivity should be used in determining which babies should be resuscitated; the question of how much quality of life should play into this decision; and the question of how much cost society is willing to bear.

To the author's knowledge, popular media have not sufficiently covered these topics. They have not adequately communicated that preterm birth and low birth weight can have severe, lifelong, extremely costly consequences nor have they broached questions of quality of life. In sum, the media have not successfully conveyed the complexity, severity or personal nature of the problem.

Issues to explore

This thesis aims to explore three aspects of preterm birth and low birth weight that media have largely underreported. First, the thesis will examine the personal experience of having a preterm, low birth weight baby, including the emotional, physical and financial costs. Second, it will contextualize the complexity and severity of this phenomenon, including risk factors, lack of successful prevention techniques, growing number of babies who survive with long-term disabilities and societal costs. Lastly, this thesis will investigate the increasingly important questions of ethics and quality of life related to preterm birth and low birth weight, specifically how decisions surrounding the resuscitation of preterm birth and low birth weight infants are and should be made.

Methodology

This thesis attempts to explore the complexity and severity of issues surrounding preterm birth and low birth weight. Specifically, it will examine the emotional, physical and financial costs of these conditions, as well as the ethical questions they raise. The project is a compilation of several types of research and writing techniques. I first reviewed scholarly literature to identify and build background knowledge on the most pressing issues relating to preterm birth and low birth weight. The literature included studies published in reputable medical journals, as well as trend data from the Centers for

Disease Control and Prevention. I also read articles published in national newspapers to develop an understanding of how the popular media have covered these issues. These findings helped shape the topics for each article in the series and allowed me to find expert sources to interview.

The project is comprised of a series of four print pieces. One is a long-form narrative, two are traditional news features, and the last is an alternative story form. I chose multiple writing forms to reach a broad audience. Because the issues of preterm birth and low birth weight are problems of national significance, each article is suitable for publication in a national newspaper or magazine.

Narrative: Too little: Jada's story

I decided a narrative approach would be the most effective way to demonstrate the physical strains a preterm baby faces upon arrival, as well as the physical and emotional toll the situation can take on parents. I studied Jon Franklin's *Writing for Story* (1986), which explains that a narrative work should be driven by a central complication, with several developments along the way leading to a resolution of that complication. In addition, I read the works of several more narrative authors, including Katherine Boo, Truman Capote, Ted Conover and Susan Orlean. Their work helped elucidate how to structure a narrative piece, develop characters and reconstruct scenes. Adrian Nicole LeBlanc's book, *Random Family* (2003), was particularly inspiring, as it demonstrated that a nonfiction narrative can read with as much intrigue as a novel. A social worker at UNC Hospitals helped identify a subject for the narrative. Angela Williams allowed me to follow her in fall 2007 as her preterm baby, Jada, fought to survive in the NICU. I

spent many afternoons with Angela and Jada in the NICU and took notes during my visits.

Although I witnessed most of the scenes in the narrative, based on in-depth interviews, I recreated a few, including the two children's birth scenes, the episode when Jada stopped breathing and the Thanksgiving visit. Initially, I thought I would interview Jada's doctors to gain a deeper understanding of Jada's medical condition. But I decided early on that I wanted the reader to experience what Angela was experiencing. When she was confused about what was going on, I wanted the reader to be confused. I wanted the reader to understand that Angela's knowledge of Jada's condition was fragmented, as is the case for many parents of sick children. I also wanted the reader to see the communication break down that sometimes occurs between patient and health care provider.

Most of the physicians and nurses remain unnamed for two reasons. First, given the nature of rotations and shift work, many of the medical personnel remained rather anonymous to Angela. Second, leaving names out allowed me to observe situations in which I otherwise may have had access issues, given the fear of HIPAA violation. This piece runs approximately 5,000 words.

Overview: Small babies, big challenges

The overview contextualizes the complexity and severity of issues surrounding preterm birth and low birth weight, including risk factors, the lack of prevention techniques, growing number of babies who survive with long-term disabilities and societal costs. The piece is a traditional news feature, which I have studied and practiced time and time again in journalism school, internships and freelance writing. It also

involved interviewing experts and a “face,” then synthesizing the information into a cohesive story that might offer a fresh look at the issue. Several readings helped prepare me for this type of writing, such as *Health Writer’s Handbook* (2005) and *An Introduction to News Reporting* (2005). The piece runs approximately 4,200 words.

Cost and quality: The ethics of saving a life

This piece is also a traditional news feature, which addresses the financial, emotional and physical costs of preterm birth and low birth weight. It also discusses ethical questions relating to quality of life, such as the question of whether to save all babies who can technically can be saved? Should their potentially poor quality of life figure into these decisions? Who should be making these decisions, and who bears the financial costs? The piece runs approximately 3,000 words.

Alternative story form: The big picture

The field of journalism is changing rapidly, and journalists must learn to adapt their work. The alternative story form is one way of conveying information in a creative, non-traditional way. Under the direction of Andy Bechtel, I produced an alternative story form to demonstrate visually the morbidities and interventions preterm birth and low birth weight infants may face throughout their lives. This piece could run as a sidebar with any of the other three stories.

Expert sources

To complete the four articles, I interviewed many expert sources, including neonatologists, obstetrician-gynecologists, pediatricians, social workers, health care ethicists, mothers of preterm and low birth weight infants, and mothers with older children born with disabilities who were born preterm.

Limitations

Issues surrounding preterm birth and low birth weight are complex and multifaceted. I could touch only on a few of these problems in this thesis. Readers look for resolution, but the story of preterm birth and low birth weight is so far from completion. Perhaps the greatest strength of this series is also its greatest weakness: The end of each piece may as well end with a question mark. There are no simple solutions here. I will complete this thesis with a retrospective chapter that considers the limitations, notes additional stories that could be reported, and offers some observations for medical and health care journalists who write about complex medical topics.

CHAPTER 1

Small Babies, Big Challenges

Halle Purvis lies on her tummy on the floor of the family room. Her dark eyes peer up toward the TV, where Barney the purple dinosaur is singing. Halle sings softly along with him. After a few minutes, she stands up and pads over to her mother, her gait a bit jerky.

“Chips?” she asks her mother, Melanie Purvis. “Chips?”

Halle can’t eat much, but she does love potato chips. Melanie obliges, rustles around in the kitchen for a minute, returns with a large bag of chips and hands them to Halle. Halle sits back down on the floor and starts stuffing the chips into her mouth. She coughs. Melanie glances at her daughter instinctively to make sure she’s not choking. At 3 and a half years old, Halle can’t swallow well and receives most of her food from a feeding tube inserted into her stomach—one of the many residuals effects of her preterm birth.

Halle arrived more than three months early after just 25 weeks of gestation. She weighed 1 pound 7 ounces and spent an entire year in the neonatal intensive care unit, or NICU, at UNC Hospitals. There she struggled to survive in an environment her tiny body wasn’t yet developed enough to handle.

Preterm birth is a growing phenomenon in the U.S., where the rate has increased by a third over the last 25 years, according to data from the Centers for Disease Control

and Prevention. Now nearly one out of eight babies is born too soon, or before 37 weeks, which is dangerous for several reasons.

First, preterm birth is responsible for one-third to two-thirds of infant deaths in this country—a serious problem considering the U.S. has the second-highest infant mortality rate in the developed world, according to a Save the Children report.

Second, those infants who do survive preterm birth are susceptible to a host of potentially devastating short- and long-term health problems. Over the last two decades, medical advances have allowed physicians to save babies as young as 23 weeks. But improvements in lifesaving technology have not been followed by reductions in long-term health issues for these infants, meaning that many babies survive with severe disabilities and potentially reduced quality of life.

Most babies born preterm are also low birth weight, or fewer than 5 pounds 8 ounces. Low birth weight babies are at-risk for serious complications, as well. Around two-thirds of low birth weight babies are preterm, while the others are known as small-for-gestation, meaning they are born past 37 weeks but below a normal birth weight. Because the two conditions are often interrelated, researchers often consider them together when discussing issues related to either one.

The costs of preterm birth and low birth weight are enormous for families and society. The Institute of Medicine estimates that the health bill for preterm infants and their resulting medical conditions costs the U.S. around \$26 billion each year, a figure that does not include subsequent lifelong costs of medical therapy or other needs. That estimate amounts to \$51,600 per infant born that year. Families and insurers bear much of

the cost burden, but the government does, as well. Medicaid foots the bill for around 42 percent of preterm births.

Measuring the quality of life value against these dollars is difficult business. When a baby is born at the edge of viability—around 23 or 24 weeks—parents and physicians often have to make grueling decisions about whether to administer intensive care to the infant, who is more likely than babies born just a few weeks later to suffer long-term health problems and disabilities, if it survives. This scenario presents some complex ethical issues: Should extremely preterm babies be saved because survival might technically be possible, or should quality of life be figured into the equation? How is quality of life defined? And how much evidence exists that this particular infant will grow up to have a poor quality of life?

Apart from the difficult life-and-death decisions, the increasing rates of preterm birth and low birth weight and their resulting dire consequences beg the question of what can be done to prevent such conditions. The answer is less than comforting: No one's really sure. Although several risk factors have been identified—some of which can be minimized or eliminated—the actual mechanisms of preterm labor are not well-understood. The CDC's Healthy People 2010 calls for a reduction in the preterm birth rate to no more than 7.6 percent of live births, compared to today's rate of nearly 13 percent of live births, as well as a reduction in the low birth weight rate to no more than 5 percent of live births, as compared to today's rate of 8 percent of live births. But a lack of understanding about the conditions—and even knowledge of the risk factors—has precluded the development of reliable prevention techniques.

Risk factors

Perhaps the greatest risk factor is a woman having had a previous preterm or low birth weight birth baby, said Dr. Jennifer Niebyl, an obstetrician-gynecologist at the University of Iowa. That factor applies regardless of a woman's age.

Preterm birth and low birth weight are often viewed as problems of teenage minorities. In reality, any woman can have a preterm or low birth weight infant. But there is some truth to the stereotype.

“Nationwide, African American mothers are more likely to have preterm and low birth weight babies,” said Dr. Ed Thompson, state health official for the department of health in Mississippi, which has the highest rates of preterm birth and low birth weight in the country. “The reasons that the differences exist are not fully understood.”

Even when studies control for socioeconomic status and specific medical characteristics, black women are still significantly more likely than white or Hispanic women to deliver preterm or low birth weight babies—a fact that is thought to contribute greatly to the variation in rates among states.

Some studies have indicated that social determinates, such as chronic stress, may contribute substantially to the disparity in rates between blacks and whites, said Vijaya Hogan, a clinical associate professor of maternal and child health at the University of North Carolina at Chapel Hill. Hogan has co-authored studies linking chronic stress in blacks to bacterial vaginosis, an infection associated with preterm birth. Other studies have looked at the presence of stress at the neighborhood level, by assessing characteristics such as amount of crime in an area, and found that even such indirect stress can be linked to biological conditions that affect pregnancy, Hogan said.

It's also true that teenagers are more likely than women in their 20s and early 30s to have preterm or low birth weight babies. So teenage minorities have, in fact, contributed to the rates of preterm birth and low birth weight. But the demographics of the women giving birth to preterm and low birth weight infants have been shifting slowly over the last decade or two, and other risk factors come in to play as well.

CDC data show that in recent years, teenage pregnancies have declined, which means fewer preterm births and low birth weight babies are coming from that subset of women. On the flip side, many women are delaying childbearing into their late 30s and 40s, and those women are at an increased risk for poor pregnancy outcomes. The growing pool of older moms has contributed to the increase in preterm births and low birth weight babies.

Melanie Purvis was 39 years old when she became pregnant with Halle. She already had two teenagers. Her physician warned her that as an older mother, she was at greater risk for complications, such as preterm labor.

"They had talked about it, but since I had had the other two with no problems, it kind of went in one ear and out the other," she said. "Not me."

So she was shocked when she developed preeclampsia, or dangerously high blood pressure that caused her organs to start shutting down, and Halle had to be delivered by emergency cesarean section at 25 weeks.

Delayed childbearing and medical advances have also lead more women to turn to assisted reproductive technology, such as in vitro fertilization. Studies show that women who conceive using IVF are more likely to give birth to multiples, which greatly increases the chances that the babies will be born preterm and low birth weight. In fact,

around 60 percent of multiple births are preterm or low birth weight, according to the March of Dimes. Some studies have even shown that single babies conceived through IVF are twice as likely to be preterm or low birth weight as singleton babies conceived naturally.

In addition to those characteristics, a variety of medical, behavioral and socioeconomic risk factors exist for preterm birth and low birth weight, many of which are also indicators of a generally unhealthy population. Some of the medical factors include diabetes, preeclampsia, infections, obesity, inadequate weight gain and stress. Behavioral factors include the use of alcohol, tobacco and illicit drugs. Socioeconomic factors, such as low income and lack of education, have also been linked to preterm birth and low birth weight.

But there is a difference between identifying risk factors associated with preterm birth and low birth weight and understanding the underlying causes of the conditions. Population statistics and risk factors cannot accurately predict whether an individual mother will go into preterm labor.

Prevention

Given the great physical, emotional and financial costs of preterm birth and low birth weight and the inability to avert long-term health problems in many surviving babies, most experts agree that the solution to the growing problem will likely have to come from preventing both conditions all together. But today, effective prevention methods are largely nonexistent. Even standard prenatal care has not been shown to prevent preterm birth and low birth weight, Niebyl of Iowa said.

“Until we really understand the causes—and there are probably multiple causes—we’re probably not going to find an effective treatment,” she said.

The only medical advance that has been shown to reduce significantly the instance of preterm birth is a weekly progesterone injection, called 17P. However, the injections are effective only in women with singleton pregnancies who have previously given birth to a preterm infant.

“Preterm birth and low birth weight is really more than a maternal and child health issue,” Thompson of Mississippi said. “It is more of a women’s health issue in general.”

That’s because many of the medical risk factors for preterm birth and low birth weight are serious health conditions, such as high blood pressure and diabetes, that are becoming more prevalent in the general population. Controlling those types of conditions before pregnancy can make a difference in outcomes. But if they go unchecked before conception? “It’s too late,” Thompson said.

Even if a medical silver bullet were developed to prevent preterm birth and low birth weigh, that wouldn’t be enough, Hogan of UNC-Chapel Hill said. “It’s a mistake assuming it’s just a health problem,” she said. The solution doesn’t just rest with physicians providing treatment, but with broader community involvement, such as creating healthier environments. “The general consensus has been that personal behavior dictates health outcomes,” she said. “But people generally behave as healthily as they can. Context is the biggest determinant.”

Although reliable prevention methods haven't been developed for preterm birth and low birth weight, some state programs have shown success in reducing specific risk factors.

For years, Colorado's low birth weight rate has been one of the highest in the nation. A Colorado Department of Public Health and Environment study revealed that inadequate weight gain and smoking are two of the greatest contributors to the high low birth weight rate in Colorado. The study also identified several other risk factors, including living at high altitude, which can slow intrauterine growth.

To help combat some of the most significant factors, the department designed and administers a Prenatal Plus Program, which provides additional support to Medicaid-eligible women who are considered high risk for delivering low birth weight infants.

"Low birth weight can be addressed more [than preterm birth] by behavioral modifications," said Mandy McCulloch, director of Colorado's Prenatal Plus Program. "There are things we can do to help them gain weight and quit smoking."

The Medicaid-funded program provides multidisciplinary client-centered counseling, meaning that a team of professionals assists the women in identifying and reducing their particular risk factors.

"It's possible that the doctor would say you need to gain weight or lose weight or quit smoking. But they're giving the advice and not providing the how-to," said Sue Ricketts, maternal and child health demographer with the Colorado department of health. "These women essentially get a friend who's coaching them at all times."

A 2006 Prenatal Plus Program annual report showed that more than half the 2,137 women who participated that year were able to resolve all their risk factors. The low birth

weight rate for the women was 11.4 percent, significantly lower than the expected rate of 13.7 percent for such a high risk population.

In addition to a reduction in the expected low birth weight rate, the program also boasts a major cost savings. It estimates that every \$1 spent on Prenatal Plus saves Medicaid \$2.48. In 2006, that estimated savings totaled around \$2.9 million.

But the benefits of the program—healthier pregnancies and a 16 percent reduction from the expected low birth weight rate—underscore the difference between risk reduction and prevention. The reality is that despite some programs and strategies that help women cut their risk factors, preterm birth and low birth weight are still ever-growing problems across the nation.

Advances in care

Some medical developments over the last two decades have dramatically improved survival outcomes for the youngest babies. Underdeveloped lungs are one of the greatest dangers of preterm birth and low birth weight. Most experts agree that surfactant therapy, which was approved by the FDA in 1990, has been one of the most noteworthy developments. Surfactant is a substance that naturally occurs in the lungs, helping them to function effectively. But preterm infants often lack adequate levels of surfactant. Surfactant therapy improves lung function by providing a sufficient amount of the substance to the lungs, significantly reducing both morbidity and mortality from severe lung problems. Now babies can survive as young as 23 weeks.

A baby born at 26 weeks and placed on surfactant therapy will have fewer issues in terms of lung disease, brain injury and long-term problems than it would have had without the treatment, said Dr. Christoph Lehmann, a neonatologist at Johns Hopkins

University, one of the top children's hospitals in the country. But at the same time, surfactant pushed down the age limit of babies who can survive, and those youngest babies are more likely to have severe and long-term problems than older babies, he said.

Studies have shown that another important development, the administration of steroids to pregnant women who are about to deliver early, increases fetal lung maturation, making infants less susceptible to the severe lung problems that are so common after preterm birth.

Smaller advances have also changed the face of treatment for preterm and low birth weight infants.

"We are able to measure everything related to babies in a way that's more appropriate for babies," said Dr. Anne Hansen, medical director of the NICU at Children's Hospital Boston, which has been ranked by U.S. News & World Report as one of the top two pediatric hospitals in the country for the last 18 years. For example, miniature blood pressure cuffs, IVs and ventilators now offer more effective and comfortable ways to care for tiny infants.

"In general, people are moving much more toward non-invasive types of technology and trying to understand the neurologic consequence of being born early," she said.

For all the major developments over the last few decades, life in the NICU is still precarious. When babies are born at the edge of viability, around 23 weeks, parents and doctors have to make grueling decisions about whether to resuscitate them. Surviving babies may face serious complications that arise after preterm birth, including brain bleeds, chronic lung disease and life-threatening intestinal problems. Babies who

experience such conditions are at an increased risk for developing long-term developmental problems.

Life in the NICU

Halle Purvis spent her first year of life in the NICU at UNC Hospitals. Her mother, Melanie, described that year as a “rollercoaster.”

“The NICU is another world,” she said.

Halle was on and off a ventilator for nearly two years and suffered from chronic lung disease, a lifelong condition. She battled unidentifiable infections and at one time was on four different antibiotics. Her heart rate would inexplicably soar over 200 beats per minute. She never cried, and her doctors thought her vocal cords were paralyzed from being on the ventilator so long. She had feeding problems. She underwent multiple surgeries. She had a narrow airway, and a few times a week, would “clamp down,” as they called it when she stopped breathing and turned blue. No one knew how the oxygen loss during the clamp downs would affect her brain function.

Each day, Melanie dropped her two teenagers off at school near their home in Bear Creek, N.C., drove an hour to UNC Hospitals, spent the day with Halle in the NICU, then drove back an hour to Bear Creek to pick the kids up from school. When Halle wasn’t doing well, Melanie stayed longer. Her husband, Greg, visited the hospital once or twice a week, as work permitted. Occasionally, when Halle had surgery, they stayed overnight at the hospital.

Like many couples with sick children, the situation strained Melanie and Greg’s marriage, especially when they disagreed about treatments for Halle.

“You argue over what she needs, but you both want the same thing,” Melanie said.

Because Halle arrived so early and so underweight, Medicaid automatically covered her medical expenses. The bill would likely have been at least several million dollars. Although Medicaid footed the medical bill, the Purvises struggled to pay for gas to get them to and from the hospital.

“It was the longest year of my life. It was a very testing year,” Melanie said. “You wanted the world to stop—to be put on pause until this was over.”

When Halle was 6 months old, she was struggling on the ventilator and couldn’t be weaned off it. She was clamping down regularly. Melanie and Greg met with her team of doctors to decide how to proceed.

“Are we fighting a losing battle?” Melanie asked them. Most of the doctors on the team thought they were, Melanie remembered. But one suggested a tracheostomy, or cutting an opening through her throat into her windpipe to create an airway, might help Halle.

They agreed to try the tracheostomy, or trach, and Halle responded fairly well to it. She went home two days shy of her first birthday, but remained on the ventilator and trach and required at-home nursing care for much of the next year.

“I just felt like my stomach was in my throat for about two and a half years,” Melanie said. “You wanted an insurance policy saying she would still be here a month from now.”

Halle’s NICU stay was longer than most, but the physical duress she underwent and the emotional toll the experience took on her family is common.

Besides the obvious anxiety, many families with babies in the NICU also struggle to get time off work, acquire child care for their other children or pay for transportation to the hospital, said Marty Hudson, a neonatal social worker at the renowned Children's Hospital of Philadelphia. "They're going to need flexibility." Social workers often work with families to reduce these additional burdens while their babies are in the hospital and help them cope with the emotional drain.

When their time comes, many babies leave the hospital and live normal, healthy lives. But for others, the medical and developmental issues associated with preterm birth and low birth weight last well beyond the NICU; they can become lifelong problems.

Life after preterm birth

The youngest, smallest and sickest preterm and low birth weight babies in the NICU are the most likely to develop long-term health problems. In fact, half of extremely preterm infants, that is, babies born under around 26 weeks, develop neurodevelopmental and motor impairment, according to the American College of Obstetricians and Gynecologists. Babies born later tend to do better both in-hospital and in the long-run.

The most common chronic problems associated with preterm birth and low birth weight run the gamut from neurodevelopmental to physical to behavioral issues, including mental retardation, cerebral palsy, blindness, deafness and attention deficit hyperactivity disorder. These infants often experience speech and growth impairment. They are at higher risk for poor school performance, as well, said Dr. Diane Marshall, director of UNC's Special Infant Care Clinic. Some preliminary data suggest they may also be more likely than term babies to develop autism, she said.

The Special Infant Care Clinic provides developmental follow-up for high-risk babies leaving the NICU, such as those born before 30 weeks and those with brain bleeds or chronic lung disease. The clinic screens babies, typically at six-month intervals, as supplemental care to their regular pediatrician visits, until they are around 2 years old. It can take a while to distinguish long-lasting problems, such as cerebral palsy, from delays in developmental milestones that children may catch up with over time, such as feeding issues.

“By 2 years of age, we feel that we can pretty much identify those kids that have a delay that’s not going to be so transient, and we have them plugged in to appropriate services in the community,” said Marshall, who was one of Halle’s doctors. Those services may include speech, occupational or physical therapies, or visits with specialists, such as neurologists or nutritionists.

It can still be difficult to determine the extent of children’s developmental issues when they’re toddlers. It can be even harder to prepare families for what may or may not come.

“It’s not really over until it’s over. Even when a baby does well, we say we’re going to have to get to school to see what happens, said Dr. Hallam Hurt, a neonatologist who runs the Neonatal Follow-up Program at Philadelphia Children’s Hospital. “It’s very tough to be the parents of a preemie.”

While many medical centers with a high level NICU offer some kind of developmental follow-up for at-risk preterm and low birth weight infants, services vary greatly from one to the next, Marshall said. That’s one reason why the impact of these clinics is tough to measure.

“I don’t think there’s really good data on the effects the clinics have,” Marshall said. “It’s very hard research to do.”

Just before she turned 2 years old, Halle was weaned off her ventilator and trach. She began to walk almost immediately after the tubes that restricted her were gone. Finally, she was “wireless,” as the family called her.

Today, at 3 and a half years old, she’s about a year behind average kids both physically and developmentally. She works with a speech therapist, an occupational therapist and a physical therapist. She still passes out and turns blue when she falls down or feels pain. Her next major task will be to learn to swallow better so she can eat enough to be taken off her feeding tube. Her doctors hope that she’ll be caught up in growth and development by the time she reaches school age.

“Everything’s fixable now pretty much. It’s not life or death so much now,” Melanie said. “She’s always going to be quirky, though, but I wouldn’t trade it for anything.”

Only time will tell how Halle will function as a school-age child, adolescent and adult. But for now, her family is just thankful that she is here and not attached to wires.

Moving forward: A shifting focus

Today, the focus of research is moving toward improving quality of life for the babies surviving with disabilities.

“The shift has really gone from mortality to morbidity. It affects every part of our care,” Hansen of Children’s Hospital Boston said. “Research is much more focused on long-term developmental outcomes—not just graduating from the NICU, but at school age, as adults.”

“A lot of research is going on to protect brains and make brains grow in the best possible way,” Lehmann of Johns Hopkins said.

Over the last decade, most of the increase in the preterm birth rate has been driven by late preterm births, or those babies born between around 32 to 36 weeks, said Joann Petrini, director of the Perinatal Statistics Center at the March of Dimes. Late preterm babies are less likely than the earliest babies to have severe problems. But the latest research has demonstrated some surprising findings.

“Until recently, late preterm birth was seen as a relatively benign outcome, but more and more research is showing transient problems,” Petrini said. Those problems can include respiratory and feeding issues, temperature instability and jaundice, among other things, according to a recent Lancet article.

“To everybody’s sense of shame, even kids in this newly defined term of late preterm babies have subtle changes in their neurodevelopment that we don’t have a good way of measuring,” Hansen said. Advanced imaging techniques can now pick up more subtle changes in the brains of these infants, and long-term studies are starting to show these infants have more behavioral and cognitive problems than anticipated.

“We have to find out some way to use that information,” Hansen said. “All the equipment is dazzling. That’s all great, but how can we get these kids to turn out as close as possible to term infants?”

Figure 1. The Big Picture

<div><h1>The big picture</h1><h2>Preterm birth and low birth weight</h2><p>Preterm birth and low birth weight are growing problems in the U.S., where one out eight babies is born preterm and one out of 13 is born low birth weight, according to the Centers for Disease Control and Prevention. The rates of both conditions, which are often interrelated, have been increasing for decades. They are physically, emotionally and financially costly.</p></div>	
<div><h3>TERMS</h3><p>Full term: Born between 38 to 42 weeks of gestation.</p><p>Preterm or premature: Born before 37 weeks of gestation.</p><p>Late preterm: Born between 34 to 36 weeks. Most of the increase in preterm births has been in this category.</p><p>Extremely preterm: Born before around 26 weeks.</p></div>	<div><h3>Q&A: OUR TINIEST BABIES</h3><p>What are the risk factors for delivering a preterm or low birth weight baby? Many risk factors have been associated with these conditions, including a previous preterm birth, black ethnicity, advanced maternal age, use of assisted reproductive technology, smoking, inadequate weight gain, infection and birth defects.</p><p>Can these conditions be prevented? Not always. Some risk factors, such as smoking and inadequate weight gain, can be reduced. For women who have already had a preterm birth, a weekly injection of the hormone progesterone has been shown to reduce the risk of subsequent preterm birth. But the mechanisms of preterm birth and low birth weight are not well understood, making widespread prevention virtually impossible.</p><p>What are some of the most worrisome complications that can happen when a preterm or low birth weight baby is still in the hospital? Difficulty breathing, severe brain bleeds and serious intestinal problems are some of the most common and dangerous complications that preterm and low</p></div>

Low birth weight:

Weighing fewer than 5 pounds 8 ounces at birth, regardless of gestational age.

NICU: Neonatal intensive care unit, where preterm and low birth weight babies typically spend their first days, weeks or even months.

Chronic lung disease: The continued need for supplemental oxygen at 36 weeks post-conception.

Edge of viability: Babies born around 23 to 25 weeks. Parents and physicians may need to determine whether to provide intensive care.

Quality of life: A subjective concept describing physical, emotional and even spiritual well-being.

birth weight infants face shortly after birth and while still hospitalized. Intervention can reduce some risks, but any preterm or low birth weight baby has to be monitored carefully.

Are preterm and low birth weight babies typically healthy when they leave the NICU? Some are, but many of these infants experience lifelong physical, developmental and behavioral problems, such as cerebral palsy, mental retardation, blindness, deafness and attention deficit hyperactivity disorder. Preterm birth is responsible for about half of all congenital neurological disabilities. Many of these children require speech, occupational and physical therapy, as well as care from several medical specialists.

How much do these conditions cost? A lot. A 2006 Institute of Medicine study showed that preterm births cost the U.S. around \$26 billion in 2006. And that estimate doesn't incorporate lifelong costs of medical therapies. Medicaid covered the tab for 42 percent of preterm births that year.

Where is research in this area heading? Babies are surviving younger and smaller than ever before, but reductions in long-term health problems haven't followed. Now research is moving toward improving quality of life for these infants. One major aspect of current research focuses on creating ways to help the brains of preterm babies develop properly—one of the biggest problems these children face.

What is life like for preterm babies as adults? Few studies have followed preterm babies to adulthood. However, one set of studies by Saroj Saigal et al. surprised many physicians when it revealed that, despite disabilities, young adult participants born extremely low birth weight had only minor differences in educational attainment, employment and behavioral issues compared to a normal birth weight control group. They also rated their quality of life indistinguishably from that of the control group.

CHAPTER 2

Too Little: Jada's Story

Angela Williams sits in an arm chair, gazing down at the neatly swaddled bundle in her arms. Nestled deep inside the layers of blanket lies Angela's tiny daughter, Jada Rose. It's feeding time, but Jada isn't nursing or drinking from a bottle—she can't do those things yet. Instead, a string-sized tube snakes through her mouth, down her esophagus and into her stomach, delivering an eighth of a cup of breast milk Angela pumped earlier. As the milk flows into her belly, Jada sleeps.

“I don't know what color her eyes are yet,” says Angela, 25, smiling down at the baby.

Jada was a preterm baby, a growing phenomenon in the U.S., where nearly 13 percent of babies are born too soon. She arrived more than three months early at 25 weeks, weighing 1 pound 11 ounces, or about the same as a sweet potato. She was also classified as low birth weight, like 8 percent of infants born in this country. Her body stretched 13 inches. She has more than doubled in weight since her birth 52 days ago, but her official due date was supposed to be six weeks from now. According to her doctors, Jada might be home in five weeks, just in time for Thanksgiving.

The milk flows inaudibly through the feeding tube, and Jada squirms a little now and then—her soft pink arms pressing gently against the blanket. She squawks softly like a bird from time to time, but she hasn't been able to cry yet. Mostly she sleeps and grows and fights to stay alive.

Angela looks on knowingly. She's done this routine before. Jada is her second preterm baby. Black women, like Angela, are significantly more likely than white women to deliver preterm infants. For some known reasons, such as higher rates of diabetes and hypertension, and some unknown reasons, they're also twice as likely as white women to have low birth weight babies.

Jada shares this room at UNC Hospitals' neonatal intensive care unit, or NICU, with eight other babies. The NICU at UNC Hospitals admits 700 sick babies each year. Half the babies are covered by private insurance; Medicaid pays for the other half. Shades drawn, the large room is dim and crammed with machinery that supports babies in the most basic task of all: living. Here, parents and nurses speak in hushed voices, not wanting to disturb the other nervous families. Oxygen whirrs into babies' nostrils, and the smell of new baby mingles with the smell of hospital antiseptic. Alarms sound endlessly, indicating that an infant's heart rate is too low or that she's breathing too rapidly. Here, each breath feels like a gift that might not be bestowed again.

It's hard to see Jada's face beneath the elephant-trunk-like tubing that runs over the length of her tiny head and attaches to plastic prongs that rest inside her nostrils. Thick blue elastic straps tightened across her tiny cheeks hold the prongs in place. Whirr-hiss-whirr-hiss. The elephant trunk, called a CPAP, delivers air pressure into her lungs—and sometimes extra oxygen if her saturation is low—so they don't stick together and collapse when she breathes. Undeveloped lungs are one of the great dangers of prematurity and low birth weight.

Angela snuggles tiny Jada against her large breasts. Gold lettering scrawled across her white T-shirt reads: “They’re real and they’re fabulous.” She smiles down at Jada, in awe of the beautiful baby in her arms.

Angela is curvy. Her dark hair is asymmetrical, closely shorn around one side of her round face, but angled in the back so that longer blond-streaked hair falls to her chin on the other side. Gold earrings dangle from her ears. Gold and diamond rings adorn her fingers. Her eyes are dark, her skin soft. Thick black ink etches out block letter initials on her upper left arm. A tattoo on her left wrist reads “Jalen,” the name of her 3-year-old son, in thin black script. Her right wrist is bare, but it’s reserved for another name: Jada.

“I’m gonna get it done, but I didn’t know if the ink would be bad while I was pumping,” Angela explains in her quiet but upbeat voice. The lighthearted side she shows the world sometimes belies the sadness she feels as the mother of two babies born too early and too little. Sometimes she gets depressed, worrying about her children.

“It should be normal to want to cry,” she says of moms with sick babies. “There’s something wrong if you don’t feel depressed sometimes.”

She rubs Jada’s creamy cheek with her finger. “Hey, little peanut,” she says softly.

After about an hour, all the milk has made its way into Jada’s stomach, and the nurse returns. It’s quite a process moving Jada from Angela’s lap back to the plastic bassinet rigged with technology that keeps her alive. The nurse gingerly lifts the baby out of Angela’s arms. Alarms sound as the elephant trunk gets displaced, and Jada starts breathing irregularly. But in a few seconds, she’s back in her bassinet, and her vital signs are back to normal.

The nurse unwraps Jada's blanket cocoon, exposing her creamy skin and a surgical scar running across her left shoulder blade. Two weeks ago, Jada had surgery to repair a part of her heart that had not fully formed, a condition common in preterm infants. She spends most of the day lying in a doll-sized diaper under a heat lamp because her body can't regulate temperature yet. A mess of wires entangles the plastic bassinet. The nurse sticks a gold heart-shaped foil sensor to Jada's tummy, which monitors her body temperature. She straps a cuff around Jada's tiny foot to measure her oxygen saturation levels. She removes the now-empty syringe of milk from the end of the feeding tube and attaches another one. When Jada burps, the expelled milk travels back up the tube into the empty syringe to be measured to ensure Jada is digesting enough milk.

Other wires, connected to Jada's body by suction cups, measure her heart and respiratory rates. A monitor off the side of the bassinet registers the numbers these wires pick up. When the numbers rise or drop to unsafe levels, alarms sound. The monitor alarms seem to beep constantly; something is always a bit off in one direction or the other.

Red felt letters run across the top of the monitor spelling, "JADAPOO," the nickname Jada's primary nurse, Julie Steffl, calls her. Julie also cared for Jada's big brother, Jalen, when he was in the NICU. She's the one Angela trusts and the one Angela asks for help to understand the medical information the doctors give her. Four photographs line the bottom of the monitor: one of Jada wearing her daddy's wedding ring around her wrist; one labeled "Jada's first dress," showing Jada dwarfed by a pink doll dress; one of Jada with a red bow stuck to her head; and a smiling photo of her big

brother, Jalen, the day he met his “sissy.” Jalen was also born at 25 weeks, and he weighed even less than Jada. He almost didn’t make it home.

When Angela got pregnant the first time, she was 22 and thought her life wouldn’t change too much. “I didn’t think I’d have to grow up,” she says. After all, her mother would help care for the baby when he arrived. While she was pregnant, she worked two jobs as a certified nursing assistant and planned her wedding to the baby’s father, her long-time boyfriend Josh. Her jobs were stressful and included heavy lifting. She sought prenatal care, and screening tests during her pregnancy revealed that the baby had an elevated chance of having Down syndrome, adding to Angela’s stress. She worried and worried. More tests showed that the first had been inaccurate. The baby’s chance of having Down syndrome was actually just one in more than a million.

Then Josh’s grandmother died. Angela had heard it was bad luck for a pregnant woman to go to a funeral, but she went anyway to pay her respects. She was six months pregnant and had gained only about 1 pound. During the funeral, she started to feel contractions. They were coming on strong, about every two minutes and lasting 30 seconds. They were painful enough to bring tears to her eyes. She couldn’t walk. But she assumed they were false labor, or Braxton-Hicks contractions. Then she started bleeding. Josh rushed her to her ob-gyn in Burlington, N.C., near their home. She was in labor. She was placed on magnesium sulfate to slow the labor and given glucocorticoid steroids to speed up the development of the baby’s lungs. An ambulance rushed her from Burlington to UNC Hospitals, which offers more advanced care for preterm babies.

The next day, Angela was fully dilated, and, like it or not, the baby was on his way. There would be no time for a baby shower, no time to decorate the nursery. Angela gave two pushes, and out came Jalen Lee, weighing a meager 1 pound 7 ounces. He spent three and a half months in the NICU. Angela couldn't hold him for a month.

"About every other day, I would get a call at work to come in, that he might not make it," Josh says, shaking his head at the memory. Jalen was in and out of surgery. His lungs didn't work properly, and he was diagnosed with chronic lung disease. His heart didn't function right. He was too young and too small and too sick.

"I had to grow up fast," Angela says. She juggled work with the 45-minute drive each way to visit her son every day. She worried about whether he would live, and she gained 80 pounds during his first few months of life. "I blamed myself for going to the funeral," she says. She also blamed herself for having a stressful job while she was pregnant, for worrying too much about the genetic test results.

After heart surgery—the same surgery Jada would have later—Jalen took a turn for the better and was released from the hospital a few weeks shy of his original due date. Angela's elation at having her baby home was tempered when she received a bill from the hospital for his NICU stay. It took her a minute to register exactly what the number was. It couldn't possibly be right: "A hundred, a thousand, a hundred thousand, a million," she remembers counting the zeros. The sum was more than \$1.2 million. Her heart sank. According to the bill, she and Josh would have to pay \$500 a month forever, which she knew, between her nursing assistant salary and the money he pulled in working at a local auto body shop, they couldn't afford. Angela no longer received health

insurance through her job because she had gone part-time just before Jalen's birth. She was on Medicaid.

As it turned out, Jalen also qualified for Medicaid and Supplemental Security Income, known as disability, because of the Williamses' low income and because he was born so early and so underweight. Medicaid, which covers half of all births in North Carolina, picked up the tab for Jalen's care, and he also began receiving disability checks totaling more than \$500 a month. Angela and Josh opened an account for him.

"He even has a little checkbook with his name on it," Angela says proudly.

Giving birth to one preterm infant is a risk factor for having another, but Angela and Josh wanted more children. When Angela found out she was pregnant again earlier this year, she wanted to be sure she did everything right to avoid another low birth weight preemie. To help her carry the baby to term, her physician prescribed weekly progesterone shots, which Josh administered. Progesterone therapy is shown to help reduce the risk of preterm birth in pregnant women who have delivered a preterm infant.

Angela also opted out of screening tests this time; if something was wrong with the baby, there was no sense in worrying about it while she was pregnant. She avoided heavy lifting at work and steered clear of activities considered by superstition to stimulate early labor, such as vacuuming and ironing.

Then one morning when she was six months along, she woke up not feeling quite like herself. She went to work but came home early to lie down. She started to get cramps and began spotting. She went back to work for her second shift, then home again to sleep.

She decided if she woke up with cramps in the morning, she would go the doctor. The next day brought more of the same, so she and Josh headed straight to UNC Hospitals.

“I ain’t stayin’ overnight,” she told an admitting nurse, still determined to carry the baby full term. She didn’t feel like she did when she was in labor with Jalen. But the ob-gyn told her to put on a hospital gown.

“You’re in for the long haul,” she told Angela.

She was put on bed rest until the baby arrived. Again, she was placed on magnesium sulfate to slow labor and given steroid injections to quicken the baby’s lung development. After three days, she was still holding out. She sent Josh home to get some sleep before he had to work the next morning. But in the night the pain began again.

“I hurt. I hurt!” she told the nurse, but the nurse couldn’t see any contractions on the monitor Angela was hooked up to. By 3:15 a.m., Angela was fully dilated, though her water hadn’t broken. An ultrasound revealed that the baby was breach; it would be too dangerous to deliver her naturally, so Angela’s physician called for an emergency cesarean section.

“No,” Angela said. “No!” She wasn’t expecting to deliver so soon. “Please call my husband,” she wailed to the nurse. I’m supposed to be pregnant right now, not giving birth, she thought.

Josh had Jalen with him, so they couldn’t enter the operating room. But Angela’s grandmother made it to the hospital after Angela had gotten an epidural, and she stayed with her until Jada arrived and was whisked away by the NICU team.

Angela spent nine days in the hospital. The day after she delivered Jada, her supervisor at the retirement community where she works called to say she was giving

most of Angela's 40 hours of work each week to another nursing assistant. Angela and Josh needed Angela's full-time income.

"But that's the last thing on my mind," Angela said. "Jada's my first priority."

The nurse turns off the lights, and she and Angela bend down close to Jada, who opens her eyes and looks around the dim room for a few seconds at a time. Jada is 53 days old.

"I ain't never seen her open her eyes so much! What do you see? A big blob?"

Angela says, laughing. "Is this a growth milestone?" she asks no one in particular.

"You two make cute babies," nurse Julie says to Angela and Josh as she checks on Jada. "You just gotta stop making them so small," she jokes.

"We're not making any more," Angela laughs. "If I have to go through this again, you might as well get me a room in the psych ward." An only child, she used to want five kids. But the possibility of another preterm baby is too much.

"The next time I could be overdue, or I might not make it to 25 weeks," she says. "I'd rather not even try. I have a boy and a girl. I'll just wait on grandchildren."

Angela cares for other people all day. Although she lost her full-time hours after Jada's birth, she continues to work about 15 sporadic hours a week at the retirement community. She works a few hours most weekday mornings, while her mother cares for Jalen. Some days, she also works 4:30 p.m. to 7:30 p.m. Between shifts, she drives 45 minutes to the hospital to spend an hour or two with Jada, then drives back to her home in Mebane to change back into her work clothes, then another 20 minutes to get to the other

side of the county for her second shift. After work, she comes home to Josh and Jalen. On weekends, she spends as much time as she can at the hospital with Jada. She's already lost her health insurance again since she just works part-time now. She's thought about looking for a steadier nursing assistant job with better benefits but doesn't want to have to take leave from a new job to care for Jada when she comes home.

"Every minute of my day I'm supposed to be somewhere. Every day," she says.

Before bed each night, Angela calls the NICU to check on Jada's status, but she's frustrated that the nurses don't give her time to ask questions, to get the details she wants to know about her daughter before she goes to sleep.

Angela is supposed to be pumping breast milk every three hours for Jada, but with the milk piling up in the refrigerator—Jada started out needing just a teaspoon every few hours and is now up to an eighth of a cup—she recently stopped.

"I'm too tired," she says. "It's too hectic."

At 63 days old, Jada is up to 4 pounds 7 ounces. Because she's finally maintaining her own body heat, she's graduated from lying around naked under a heater to wearing clothes: a pink onesy with a tiny rosebud on the chest. The heater has been turned off. This week, Jada also opened her eyes long enough for Angela to see their color.

"They're gray, which is what Jalen's were," Angela says happily. "You want to open your eyes again?" she asks Jada.

But like every other week in the NICU, Jada's progress fluctuates. A few days ago, her doctors took her off the CPAP and placed her on a cannula, which delivers air

into her nose to ensure she receives enough oxygen but no longer forces the airway open. Taking her off the CPAP is a necessary step towards learning to bottle feed—and bottle feeding will bring her another step closer to going home. Jada spent almost four days off the CPAP, and her doctors told Angela she might be home in two weeks.

“I thought she was doing good,” Angela says. “Then I come back the next day, and she’s back on the CPAP.”

Jada’s oxygen saturation was dipping dangerously low while she was off the CPAP. Her doctors worried something could be wrong with her upper airway—something in addition to the chronic lung disease that goes along with prematurity.

A nurse comes by Jada’s bassinet to ready her feeding tube. One of Jada’s doctors approaches Angela to talk about a procedure, known as a bronchoscopy, or “bronch,” the doctors plan to perform on Jada to determine the cause of her airway problem. They’ll give Jada medicine to calm her movement, then insert a breathing tube down her throat, the doctor explains. They’ll snake a tiny camera through the breathing tube to look closer at her airway, then pull out both the scope and the breathing tube together. Then they’ll put Jada back on the CPAP.

“What do you think it is?” Angela asks the doctor, who explains four possibilities. There could be something wrong with her vocal chords. The airway could be scarred from ventilators or the CPAP. It could be a cyst. Or it could be a “floppy” airway, which is common in preterm babies and occurs when the airway isn’t wide enough or stiff enough to hold its shape during breathing. The sides of the trachea stick together, preventing oxygen from getting through to the lungs. Preterm babies typically grow out of the condition without a need for intervention.

“Would any of them require a surgical procedure?” Angela asks.

It depends, the doctor says. Angela plays with her hands and keeps her eyes on Jada.

“So when can we go home?” she asks, half-joking. Everyone laughs. No one answers. The doctor leaves, and Angela is silent, her eyes still trained on Jada lying in her bassinet.

“Try not to worry,” the nurse says. “Most of the time it’s just a floppy airway.”

Later, Angela says: “If they thought it was major, they would have done something already. If they ain’t gonna worry, I ain’t.”

Angela arrives at the hospital shortly after Jada’s bronch procedure. The bronch went fine, and Jada is doing well, a nurse tells her. Angela walks away to wash her hands at the sink in the middle of the room before holding the baby. When she turns around, Jada’s monitor shows her vital stats plummeting. Alarms sound. In moments, Jada’s heart rate falls from around 150 beats per minute down to 20. Her oxygen saturation slides from nearly 100 percent to 19 percent. Her respiratory rate registers zero; she isn’t breathing. A nurse runs over and hits an emergency call button near Jada’s bed. She tears off Jada’s onsey as the code team descends.

“Get Mom out of here!” Angela remembers one of the doctors yelling.

“I was crying. I didn’t know what to think.”

A nursing assistant escorts Angela to the family waiting room. About 15 minutes later, Angela returns to the NICU to see what’s going on. Jada is breathing again. Angela

asks a doctor what happened but doesn't glean much from his explanation. She waits until Jada's stats are back to normal before she leaves the hospital, shaken.

Later that day, across the room from Jada's bed, a baby dies.

The bronch procedure reveals a narrowing of Jada's airway, as suspected. The doctors decide to perform another bronch on Jada two days later to get a better look at the problem. Angela arrives at the hospital a few hours after the second bronch. An IV from the procedure is still stuck in Jada's foot, and she's lost 3 ounces since yesterday. She's back down to 4 pounds 7 ounces.

"I want this to be done quick," Angela says, motioning around the NICU. She's ready to take Jada home. "It'll be November this coming week. I don't want to get my hopes up. But if it's going to be before Thanksgiving, you better pack up!" she says to Jada, tickling her tummy. "That would be a good holiday gift, 'cause I won't enjoy the holidays coming in here."

Within a few minutes of Angela's arrival, four doctors have congregated around Jada's bassinet for rounds. She's being treated for acid reflux, and the surgery a few weeks back successfully repaired her heart. In addition to her narrowed airway, they're also concerned that her vocal chords aren't moving well; sometimes complications from the type heart surgery Jada had can paralyze the vocal cords. They page the specialist who led the bronch to come up and explain to Angela what's going on in more detail. Angela listens to the doctors. She doesn't ask any questions.

After the doctors move on to the next patient, Angela asks the nurse who's situating Jada, "Is that why she doesn't cry?"

“It could be,” the nurse answers.

“I hope she doesn’t need surgery—then we’d have to do this all over again,” Angela says, again motioning around the NICU. “You’re not cooperating,” she says lightly to Jada.

Angela’s husband Josh hasn’t seen Jada in two weeks. He works full-time during the week, and lately, Angela’s mother, who usually takes Jalen on the weekends while Angela and Josh visit Jada, has been working extra shifts for money to buy the kids Christmas gifts.

“You gotta come home to see Santa!” Angela says to Jada.

After waiting for a few hours, Angela has to go back to work before the specialist comes around to speak to her about the bronch results. A resident takes down her phone number to pass along to the specialist.

Two days later, Angela sounds panicked and frustrated. She’s sick with a cold, so she can’t visit Jada. The virus that can cause an adult cold, respiratory syncytial virus, or RSV, can be deadly to a preterm baby with chronic lung disease, like Jada. The doctor still hasn’t called with the results of Jada’s bronch, and Angela worries.

The doctor calls the next day.

“He told me so much, but didn’t explain it,” she says. “He tried to sugar coat it, like it’s not so bad.”

But what he says isn’t good. In addition to concerns over her floppy airway, he’s worried that scar tissue left behind from a ventilator Jada was on just after birth and during her heart surgery may be blocking her airway. He says they need to have a family

meeting to discuss the next step, but he may have to perform a tracheostomy, which means cutting an opening through Jada's throat into her windpipe to create an airway. Jada would then have to live with the "trach" for two years, give or take.

Angela prays and prays. She thinks about how people would look at Jada funny if she had a hole in her neck with a tube sticking out. She wonders if she could cover it up with clothing, like a scarf, then realizes a scarf would close off the airway.

"My mind's been out of this world worrying," Angela says.

Then a few days later, as Angela is walking down the hall toward Jada's room, a respiratory therapist comes running out to meet her.

"We've got a surprise for you!" she says. She's jumpy and excited. Jada is off her CPAP again. She isn't even wearing a cannula for extra oxygen. She's breathing normally, and her vital stats are good.

Angela is in disbelief. "I never prayed so hard," she tells Julie, as she hands her a box of donuts—her usual thank-you gift to the nurse. Julie and the respiratory therapist had urged the doctors to give Jada another chance to breathe on her own before doing anything drastic. After all, she's two weeks older than she was the last time they tried it.

Angela sits down, and the nurse places Jada in her arms. "It's a fairytale," Angela says with a sigh. "I was ready to give up."

Over the next hour, nurses and doctors walk by—all showing disbelief that Jada is off her CPAP. One doctor smiles and gives the OK signal with his hand to the nurse. Today, no one mentions the possibility of a trach. If Jada continues to breathe well on her

own, like she has for the last hour, she won't need one. She's also growing well—nearly 5 pounds. But it's touch and go from here.

Angela was supposed to pick up Jalen at his grandmother's house an hour ago, but she can't tear herself away from this event. "I just can't leave because this is a first moment type thing," she says, smiling down at Jada. "Now we gotta hear her cry."

The baby next to Jada is going home. The baby's portable crib has been packed with supplies, and a nurse gives the mother final instructions. Doctors and nurses file in to say goodbye.

Angela watches. "I know our big day is coming soon, but I don't know when," she says. "My hope of being home for Thanksgiving is out the window."

Thanksgiving is just one week away. Jada's doing well; she's breathing off the CPAP and has grown to 5 pounds 6 ounces. She is 85 days old. But she has to learn to suck on a bottle and breathe at the same time so her feeding tube can be removed. She drank from a bottle once earlier in the week, but her oxygen levels dropped as she sucked. Another bottle-feeding attempt is scheduled for this afternoon. She's got to prove herself before she's discharged.

Today, Jada will also receive her new-baby immunizations.

"Jalen got his when we were getting ready to take him home, so I hope we're close," Angela says.

Release from the hospital often doesn't mean the end of medical intervention for a low birth weight preterm infant. Jada's big brother, Jalen, will soon turn 3 years old. The

chronic lung disease he was diagnosed with at birth makes him more susceptible to respiratory illnesses. He picks up colds easily, but luckily has never had to be hospitalized. When Jalen was an infant, Josh asked his doctor whether Jalen's lungs would be strong enough for him to play sports as a teenager. The doctor couldn't answer, Josh remembers. Because medical interventions have been able to save babies born at 25 weeks only in the last decade or two, few young adults who were born very preterm are around to study.

Jalen weighs in at 28 pounds—smaller than average for a 3-year-old. A few times a year, he visits UNC Hospitals' Special Infant Care Clinic, which follows up on preterm infants as they grow. His motor skills are okay, but he was late developing speech. So he works with a speech therapist twice a week and a play therapist once a week to help him learn to describe his toys and activities. The therapy does help.

"He's talking pretty good now," Josh says. The Williamses have been told by Jalen's physicians that by the time he reaches school age, he'll probably have caught up physically and developmentally.

But research shows that preterm birth and low birth weight are associated with a host of residual problems, such as neurological and developmental issues, including mental retardation, attention deficit hyperactivity disorder, blindness, deafness and hypertension. Only time will tell if Jalen has any continuing developmental problems.

On Thanksgiving, Angela, Josh and Jalen celebrate at Angela's grandmother's house. Then they're off to her aunt and uncle's to spend time with the other side of her family. Afterwards, they drive to the hospital. Josh and Jalen wait in the car—children

still aren't allowed in the NICU this time of year, so Jalen won't get to see his "sissy" today. Angela rides the elevator to the fourth floor, walks past the nursery rhyme murals dotting the walls of the NICU—giraffes and elephants, chickens and balloons—carrying a plate piled with food she's put together for Julie, who's working today. How many times has she walked this hall these past three months? She enters Jada's room, gives the plate to Julie and picks up Jada. She kisses her baby. She talks to her. As a surprise, Julie has stamped Jada's handprint onto a piece of paper, decorated the handprint and posted it on the monitor. "Mommy's Little Turkey," the artwork reads. "Happy Thanksgiving!"

Jada is still growing quickly; she weighs more than 6 pounds—a healthy weight for a full-term newborn. She's taking half her feedings by bottle now and the other half through the feeding tube. But a recent test shows she's silently aspirating, or choking on some of the milk she swallows without showing any outward signs of distress. She'll have to tolerate all her feeds by bottle for at least 24 continuous hours before she can be released. Earlier this week, she stopped breathing again and turned gray, so she's back on a cannula for extra oxygen. Putting in a trach is still a possibility, but only if she doesn't grow out of her floppy airway in the next month. Her vocal cords still aren't functioning well, but she'll probably grow up to speak—though in a raspy voice.

Angela puts Jada back in her tiny crib after 20 minutes, walks back through the mural-filled hall, takes the elevator down, and gets into the car with Josh and Jalen. They make their way to Josh's parents' house for one last Thanksgiving meal.

"Now they're saying she won't be home before Christmas, but we'll see," Angela says. "Miracles do happen."

CHAPTER 3

Cost and Quality: The Ethics of Saving a Life

While improvements in care have allowed more preterm and low birth weight babies to survive at younger ages, those youngest and smallest babies are the most likely to develop costly and severe lifelong disabilities, such as mental retardation, cerebral palsy, blindness and deafness. And some who survive initially die weeks or months later from complications while still in the neonatal intensive care unit, or NICU.

Now that survival is technically possible for many of these infants, some clinicians are wondering whether medicine has gone too far. The concept of quality of life is coming to the forefront for parents and physicians of preterm babies born at the edge of survivability as they question whether to intervene medically.

Attention in both research and clinical practice has been shifting to consider more heavily the role quality of life should play in the decision to provide intensive care to an extremely preterm infant who would most certainly die without intervention and may die or survive with severe disability even with it.

“It’s about as ethically complicated and dangerous as any ground you can stand on,” said Dr. Anne Hansen, medical director of the NICU at Children’s Hospital Boston, which has been ranked by U.S. News & World Report as one of the top two pediatric hospitals in the country for the last 18 years.

But sometimes these decisions are unavoidable. They are cause for deep thought, for great debate. They revolve around uncertainties: whether the child will die soon

regardless of intervention; whether the child will ever walk, talk, go to school or become a functional adult; whether the pain the child will endure is worth questionable outcomes; whether the goal is life or quality of life; whether the family has the emotional will to handle a potential lifetime of disability; or whether financial costs should figure in and whether they really do.

Ethical philosophies

For some people, these decisions are straightforward: A baby should be given every chance to live regardless of how dire the outlook. Any life is worth living.

But for others, these decisions are complex. To them, quality of life means everything, or at least something. The problem with decision-making occurs because the concept of quality of life is amorphous. It describes a conglomeration of physical, emotional and even spiritual well-being, but the definition remains hazy.

In medical decision-making, the four principles of medical ethics provide guidelines for some, but they don't always work when it comes to preterm babies. Beneficence means doing good for others, such as preserving life or alleviating suffering. Nonmaleficence means not doing harm to others. Respect for autonomy describes the concept that patients should have the right to decide what treatment they have, or at least be able to refuse treatments they don't want. Lastly, justice describes the rights of the patient but also broadens the issue to a societal level, such as determining how limited resources should be spent. While these ethical principles can help provide parents and physicians a theoretical basis for difficult decision-making, in regards to the care of preterm infants, they become muddled.

Because infants can't make decisions for themselves, they need proxies. That role typically defaults to a child's parents, who are legally and ethically obligated to act in the child's best interest, said Dr. Mia Doron, a neonatologist at the University of North Carolina at Chapel Hill and co-chair of the UNC Hospitals ethics committee.

But what is the best interest of an extremely preterm baby?

"Intensive care is uncomfortable and onerous, and there's probably some pain and suffering, so it's a risky and potentially harmful thing to go through," Doron said.

"[Intensive care] is not something you would want to go through if you didn't think there was a lot to be gained by going through it."

In considering medical ethics, providing intensive care to an infant to try to keep it alive could be considered beneficent, said Dr. Jon Tyson, a neonatologist and director of the Center for Clinical Research and Evidence-based Medicine at the University of Texas-Houston. But when doctors factor in the possibility that an infant might die soon or have a poor quality of life even if he or she survives, resuscitating the baby may actually be considered causing harm.

"It's not possible to apply widely acceptable ethical principles to real-world situations without sometimes running into conflicts between these principles," said Tyson, who is well-known among physicians and researchers for his extensive writing on ethics relating to the care of preterm infants.

When dealing with extremely preterm babies, the list of clashing ethical scenarios increases, causing heated debates within in the field.

"Large cohort studies indicate that the smallest and most immature infants virtually all die soon after birth if intensive care is not provided," wrote Tyson and

Barbara Stoll in a 2003 journal article. “Neonatologists who administer intensive care to these infants treat them as if such deaths are the worst possible outcomes. Yet, death following a prolonged period of suffering is clearly a worse outcome and one that occurs all too frequently in neonatal intensive care units.”

Tyson and Stoll suggest that evidence-based ethics may be a better approach rather than relying on conflicting ethical principles, intuition and expert opinion when making real-life decisions about preterm babies born on the edge of viability. In decision-making, evidence-based ethics describes the concept of using the best evidence available on the effects of intensive care on these infants and their expected outcomes.

“First of all, [evidence-based ethics] isn’t to de-emphasize value judgments,” Tyson said. “The hope would be that consideration of this evidence would promote treatment decisions that over time become more apparent, less arbitrary and more broadly acceptable.”

Applying this technique would mean considering factors such as those Tyson calls the primary determinants of outcome: gestational age, sex, birth weight, birth weight by gestational age, whether and when the baby received steroids before birth to quicken lung maturity, and whether the baby is a singleton or one in a multiple birth.

Depending on these factors and combinations of factors, a baby has a better or worse chance of benefiting from intensive care. Using this approach, intensive care should be provided only when credible evidence indicates the “benefits outweigh the burdens,” Tyson and Stoll wrote.

The concept sounds like a pretty good one, perhaps even an obvious one to non-practitioners. Except that robust data on physical, mental and emotional outcomes for

these infants are lacking, often throwing decision-making into a gray area. That information is not available for a few reasons.

First, long-term outcome studies are difficult and expensive to perform, and few have been done. Second, medical technology and care practices change so quickly that data from young adults born 20 years ago may or may not reveal all that much about babies born and cared for with today's technology.

Third, rates of preterm babies who survive and survive without disabilities vary greatly from medical center to medical center, making comparisons among them difficult. That means such statistics have to be considered carefully when making life-or-death decisions.

Those realities make some physicians hesitant to rely on available data when deciding whether to provide intensive care to an extremely preterm infant. Dr. Sheldon Korones, a neonatologist at the University of Tennessee, is one who hesitates. Korones admits a different attitude toward intensive care from his friend and colleague Tyson.

"For 40 years, my reaction from the beginning has been to give life a chance," he said. "The heroic extent of my efforts will depend on how the baby is responding, but I don't know what he is going to do when he gets to school."

For Korones, the scientific data simply aren't out there to determine whether a specific baby will survive or have a high quality of life—whatever that means.

"Every baby is a new study and a new statistic," he said. "I cannot decide what to do with a baby based on what I did with a baby yesterday. I look at the situation and do what we can."

While some say ethical principles and data—or lack thereof—play a role in making these tough decisions, adding quality of life as part of the equation is also a complex issue.

For starters, no one knows exactly how to define quality of life.

“Quality of life is a subjective term. It means different things to different people,” said Marty Hudson, a neonatal social worker at the renowned Children’s Hospital of Philadelphia. “In many cases, what the medical staff may consider a poor quality of life is different from what a family might consider a poor quality of life.”

Surprising outcomes: Quality of life

Although few studies have looked at quality of life of preterm or low birth weight infants, one set of medical studies has turned heads.

Dr. Saroj Saigal, a neonatologist at McMaster University in Canada, and colleagues have produced some of the most well-known and well-designed follow-up studies of extremely low birth weight infants in the world. They followed a cohort of around 160 infants born between 501 grams and 1000 grams—or about 1 to 2 pounds. Looking at both functional and health-related quality of life outcomes, the researchers followed these infants through school-age, adolescence and early adulthood, comparing their outcomes to a control group of normal birth weight peers. What they found surprised the researchers, let alone the rest of the world.

When the children were around 8 years old, the researchers developed objective methods to assess how health care providers perceived the health status and health-related quality of life of these children. Of the extremely low birth weight group, 27 percent of the children had neurodevelopmental disabilities, compared to just 2 percent of children

in the control group. The health care professionals perceived that children born extremely low birth weight experienced a significantly lower health-related quality life than did the control group of normal birth weight children.

When the children become adolescents, Saigal and colleagues followed up with them again. This time, they developed the first study to assess objectively health status and health-related quality of life from the perspectives of the children and parents themselves. They found that overall, the extremely low birth weight cohort rated themselves as having a significantly lower health-related quality of life than their control group peers. However, the majority of the individuals in the extremely low birth weight group actually rated themselves as having a quite satisfactory quality of life—one that was indistinguishable from the control group ratings.

“We found to our surprise that the children rated their quality of life very high, even if they were blind and had cerebral palsy,” Saigal said. “At that time, it caused a lot of skepticism. People thought maybe the children didn’t know what they were talking about, that they were replying what we wanted to hear.”

At adolescence, half to three-quarters were still having major difficulties in school. Saigal hypothesized when she followed up in adulthood that they would be less educated than normal birth weight controls, unemployed or working blue collar jobs and still have major behavioral problems.

But that’s not what they found.

“We were astounded,” Saigal said.

The study, published in 2006, showed that the adults born extremely low birth weight, despite their disabilities, had only minor differences in educational attainment,

employment and behavioral issues compared to normal birth weight controls, and those differences were not statistically significant. The majority of them were even living independently. Their self-assessed quality of life ratings were indistinguishable from the ratings of the control group.

“People thought they would be a burden for the rest of their lives,” Saigal said. “But in everything, it was astounding how well they had adjusted. You come to the conclusion that I.Q. isn’t everything. People can make the most out of it.”

Despite their disabilities, these children were recovering slowly all the way through early adulthood. They were learning to compensate, to the amazement of researchers and clinicians.

“What we are able to do now is to help [parents] make an informed decision, which we didn’t know how to do when I started doing follow-up,” Saigal said. “Parents should be told of all the disabilities likely, but that there is some light at the end of tunnel. It’s a long haul.”

The studies have opened eyes and generated much discussion in the field.

“Research shows that physicians tend to rate a diminished neurologic state as much worse in terms of quality of life than parents and families, so I think this was very surprising to physicians,” neonatologist Doron of UNC said. “It certainly has made a huge difference in how we counsel parents, and I want to say it’s made a big difference in the field.”

In addition to determining how quality of life fits in to decision-making, another issue can’t be avoided when considering preterm infants: cost.

Cost of care

Preterm birth is immensely expensive for families and society. An Institute of Medicine study estimated that preterm births cost the U.S. more than \$26 billion in 2005 alone. That's \$51,600 per infant born that year. And it's not just families and private insurers who are picking up the tab. Medicaid covers around 42 percent of preterm births.

While most people would probably cringe at the thought of placing a monetary value on any life, the principle of justice reminds us that resources—especially when it comes to health care—are limited.

So how does cost figure into a decision of whether to administer intensive care to an extremely preterm infant?

“Realistically in our society, cost doesn't figure into it, because the way we organize our medical care is heavily loaded toward paying for intensive care,” Doron said.

However, in less apparent ways, cost does play a role.

“I think people are avoiding these decisions,” Tyson of the University of Texas-Houston said. “But the truth is, they're being made implicitly.” Someone is deciding what resources will be devoted to each department in the hospital, how many beds the NICU will have, how well it will be equipped compared to other departments.

“A fundamental issue is how are you going to judge what the return is on a health care dollar?” Tyson said.

If an extremely preterm baby is going to die, it will probably die within a few days, Doron said. So most of the money spent in the NICU pays for surviving babies, though many of them will have at least mild or moderate disabilities. Nonetheless, if you

compare the number of years a preterm baby could live—and even make adjustments for reduced quality of life—to the number of years an adult might live after requiring intensive care, the baby wins out.

“It turns out the NICU is really cost effective, like 10 times more so [than adult intensive care],” Doron said.

A future of policy or choice?

For all the complexities and ethical dilemmas surrounding decision-making for infants at the edge of viability, virtually no laws govern decisions made specifically for extremely preterm infants.

“A lot of these ethical decisions are made very locally by individual physicians or groups or hospitals or medical societies,” Doron said. “But there’s certainly no national standard.”

No hard and fast rules dictate whether physicians or parents get the final say. When a baby is born before around 23 weeks or after around 26 weeks, hospital policy usually dictates whether intensive care be administered, barring other circumstances. For cases in the grey zone between 23 and 26 weeks, parents typically make the decision with the help of physicians. But that’s not always the case.

“There have been two or three times when parents insisted that I stop treatment, and I thought that would be tantamount to murder,” Korones at Tennessee said. So he didn’t.

Although some hospitals enact policies that dictate the provision of intensive care within that grey zone, some physicians disagree with this approach.

“The information is not there,” Korones said. “And this is why these policies that come out that are one-size-fits-all—I don’t think they’re appropriate.”

Some state governments have attempted to implement cut-off points under which they will refuse to cover medical costs for extremely preterm infants. Oregon is perhaps the most well-known example. In the early 1990s, the state proposed a health plan that would offer coverage to more people at the expense of covering certain conditions. Quality of life was one of the considerations used to cross these conditions off the list. It would have essentially drawn a line in the sand for extremely preterm babies. Infants born weighing fewer than 500 grams, or about 18 ounces, would be ineligible for extensive life support. The U.S. Department of Health and Human Services shot down the plan, citing discrimination against the disabled.

But in this era of health care crisis, health care dollars will need to be stretched more efficiently. Policies, such as the type Oregon proposed, might crop up again in health plans. But whether those changes will come from the federal, state or hospital level or a combination of all three remains to be seen.

Policies that guide decision-making for preterm infants aren’t just about money, though. Sometimes they’re about protection from a culture of increasing litigation. Sometimes, at the end of the day, policies are just easier to stomach than having to decide the value of someone else’s life.

“There is refuge in protocol,” Korones said. “People want decisions made for them.”

CHAPTER 4

Reflections and Conclusions

Preterm birth and low birth weight were not easy topics for me to cover. Overall, the project proved to be an emotional one because I went beyond just reporting the numbers and put faces—parents who had endured the effects of having a preterm or low birth weight baby and the babies themselves—behind those statistics. As a result, at times I had to abandon the project for a day or two to recharge. I lost sleep wondering whether the horror of preterm birth would one day invade the lives of my sisters or my friends. Whether the tiny baby who became the face of one story I pursued would live through the night. Whether I would some day have to decide whether my own baby should be given a chance to live.

In many ways, I found the topic didn't engender objectivity—as may be common in many medical topics that involve a life-or-death component. Often my personal feelings of empathy and sympathy surged. But what topic worth writing about really does lend well to objectivity in the most literal sense of the word? Once I had grappled with the research about preterm birth and low birth weight and spent time in the neonatal intensive care unit, or NICU, I realized just how far-reaching and terrifying these conditions are. While working on the series, I felt as if I had become an advocacy writer. Perhaps developing such an attitude should be a journalist's nightmare. To me, it mattered to write about something that affects so many.

Other limitations sprung up along the way. For example, I was surprised by the lack of strong data on outcomes of preterm and low birth weight babies. One of the greatest problems is that outcomes vary greatly from medical center to medical center, making it difficult to generalize outcomes across centers. Long-term outcome studies are also notoriously difficult to fund, let alone complete. And young adults who were born preterm two decades ago may have received vastly different treatment than today's babies. Those circumstances made it tough to sum up information on the effects of preterm birth and low birth weight in ways a lay audience could understand.

The ethics and quality of life article presented a few additional limitations. Defining quality of life and determining its place in medicine are delicate tasks, at best. People don't want to talk about these issues to a reporter, probably because they didn't want to be judged either personally or professionally on their ethical leanings. So at times it was difficult to get at what sources really thought about the toughest ethical issues. I also didn't feel comfortable profiling a family who had to decide whether to resuscitate their baby. I didn't want to come off as judging them one way or another, or open up some of the most trying decisions of their lives to public judgment. The story might have been more compelling with a face, but it didn't seem appropriate to use one. On the other hand, my sensitivity may have actually resulted in a lost opportunity for a family to convey their personal experience to others.

Other limitations were more typical. For example, it's challenging to get a physician on the phone. It's even more challenging to get him or her to say things that aren't riddled with jargon. Many of them seemed nervous—understandably so—to say anything that was not their hospital's party line.

In addition, the topic might have been too broad to cover in one series. I started out wanting to show the depth of the problem in a way that I hadn't seen media undertake. As I worked on the series, I discovered that any subsection of any of the articles could have been a series on its own. I hope the broad nature of the series does not dilute its poignancy.

Conclusions

Preterm birth and low birth weight are complex issues that could be approached from a variety of angles. I would caution journalists who pursue this topic or any other intricate medical issue to choose carefully their depth of focus. Broaden a project too much and it quickly overwhelms readers. It loses its effect. But narrow the scope too tightly and readers lose the greater significance of that piece in the larger puzzle.

I have also found that genuine interest in a topic will take you a long way in reporting. When it's obvious that you care about what you're writing—that you're writing about something because you recognize its importance and the need for more coverage of the issue—phones calls get returned and honest voices often appear on the other end of the line.

With those observations in mind, I recommend a list of further story ideas that stem from, or precede in some cases, the topics of preterm birth and low birth weight.

- My research and reporting revealed that better brain imaging techniques coupled with the results of fairly recent outcome studies show subtler neurological abnormalities in many people who were born late preterm than previously realized. It would be interesting to approach this topic in three ways. First, improvements in the technology itself are fascinating. Second, the

effects of late preterm birth, which is really driving the increasing rates of preterm birth as a whole, are appearing to be more significant than previously understood. This phenomenon is a new and growing area of research. Third, now that technology is picking up on subtler neurological abnormalities, where is research headed to eliminate these problems?

- Quality of life considerations and the possibility of rationing care will only become more important as the current health care crisis expands. This topic would be interesting to follow—both in general and with regards to preterm birth—as federal and state governments look for solutions to health care financing problems.
- Media have picked up on the fact that many women are delaying childbearing past 35—known as advanced maternal age. But much of the coverage has focused on infertility in this group of women. However, media have largely neglected another important aspect of the story: the potentially negative consequences of advanced maternal age on pregnancy. This topic will become more important as the average childbearing age continues to rise.
- Similarly, stories covering assisted reproductive technology have exploded in recent years. But many of those stories focus on the difficulty of becoming pregnant and the amazing technological advances that allow more women to conceive. However, assisted reproductive technology, such as in vitro fertilization, can lead to poorer pregnancy outcomes, even in singleton pregnancies. One article could reveal the risks of in vitro that are so often neglected in lieu of happy conception stories.

- Lastly, many of the risk factors for delivering a preterm or low birth weight infant are indicators of a generally unhealthy population. Media cover the increasing rates of major conditions, such as obesity, heart disease and diabetes in the U.S. population. But those conditions can also lead to additional health concerns. One story could explore the less-reported complications from obesity, heart disease and diabetes, such as poor pregnancy and surgical outcomes.

At the end of my thesis proposal, I made the following observation: “Readers look for resolution, but the story of preterm birth and low birth weight is so far from completion. Perhaps the greatest strength of this series is also its greatest weakness: The end of each piece may as well end with a question mark. There are no simple solutions here.”

And so I pose a final question to readers, to researchers, to parents, to physicians, to anyone who can’t bear to think of a baby suffering: What can be done to reduce further the dire immediate and long-term effects of preterm birth and low birth weight, especially in a country that has led the world in large part with medical advances?

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